

SEAMAN, MEGAN M., Ph.D. Caring for the Caregiver: Exploration of Sibling Connection and Social Support in Relationships of Adult Siblings Caring for Aging Parents with Dementia. (2015)
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There is a growing population of aging parents with dementia and subsequent obligations of adult children to provide care for them. Approaches to helping adult siblings care for their parents are centered on primary caregiver network models that overly focus on instrumental support and the integration of formal care into the system of dementia caregiving. Unfortunately, models that exist do not address the unique caregiving sibling connections or social support that are perceived and experienced in the dementia care system, which may prove more beneficial than instrumental assistance in helping family caregivers. To address the gaps in dementia care literature and practice, this dissertation study explored the perceptions and experiences of sibling connections and social support between adult siblings caring for their aging parents with dementia.

The current study involved interviews with five sibling dyads of families living in the Midwest who were in the process of caring for a parent with dementia. Ten siblings (two from each family) completed demographic questionnaires and independently participated in semi-structured interviews about their experiences and perceptions of dementia care, including their perceived social support and sibling connection. In cross-family analysis, four superordinate clusters and 18 superordinate themes were found in participants' narratives.

Results of this study confirm the importance of examining dementia concerns and providing assistance and resources from a systemic and contextual paradigm to adult

siblings who are caregiving for a parent with dementia, rather than working from a primary caregiver network model. Additionally, instead of medical and instrumental tasks taking the forefront of support in dementia caregiving, providing different levels of mental and emotional social support seemed to be most important in balancing the dementia caregiving system. Moreover, cultural guides related to ethnicity, religion, and generational differences proved to be important in helping caregivers deal with and understand their parents' cognitive decline. Findings from this study support an expanded way of helping and understanding adult sibling dementia caregivers' experiences and perceptions of sibling connections and social support from a family systems/ecological model.

Keywords: adult siblings, aging parents, dementia caregivers, caregiving, cognitive decline, dementia, ecological systems, eldercare, familial care, family systems, filial care, formal care, interpretive phenomenological analysis, phenomenology, qualitative research, sibling connection, sibling relationships, siblings, social support

CARING FOR THE CAREGIVER: EXPLORATION OF SIBLING CONNECTION
AND SOCIAL SUPPORT IN RELATIONSHIPS OF ADULT SIBLINGS
CARING FOR AGING PARENTS WITH DEMENTIA

by

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Approved by

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To Jen and Ry, my beloved sister and brother, whose love and acceptance inspired me to help siblings across the lifespan find support and healing in their own sibling relationships.

APPROVAL PAGE

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CHAPTER I

INTRODUCTION

More and more adult children are taking on the roles of caregivers to their aging parents. It is estimated that 10 million family caregivers in the U.S. are adult children (MetLife, 2011). In the context of caring for aging parents, caregiving might include emotionally consoling parents who have lost a spouse or a friend, providing assistance with activities of daily living, or taking responsibility over legal and financial decisions for parents, or all of those responsibilities. With that in mind, one might picture caregiving siblings working together to provide assistance for their parents in the aging process. Additionally, one might imagine siblings supporting one another as they come to terms with their new roles, responsibilities, expectations of filial care, and personal emotions and thoughts about their parents' and their own mortality. It is a sunny picture of family connection in a developmental process, over a lifespan, and across generations. This is what we imagine the experience would be, or should be. It is an image of a unified system of sibling-to-sibling-to-parent support – a kind of Norman Rockwell painting showing sustaining closeness and love for families and the beings that make up their systems.

What is known, however, is that a multitude of reasons contribute to family caregivers being charged with the task of taking care of aging adults. Unfortunately, however, the warm image of family support is often a rather romantic representation of

reality. In actuality, caregivers often feel stressed and burdened by the additional responsibilities, they experience a lack of connection and help among their siblings, and they perceive a lack of social support. Accordingly, the unified caregiving system of support is more complicated a picture than the ideal that Norman Rockwell may have painted.

The reality is that the population of adults aged 65 years and older is growing. Currently, there are 40.3 million people in the U.S. age 65 years and older, which makes up 13% of the general population (Brandon, 2012). Additionally, 80% are living with at least one chronic health condition, such as conditions related to cognitive decline (CDC & the Merck Company Foundation, 2007). Moreover, many aging adults do not have the assets to pay for out-of-pocket healthcare costs where Medicaid and Medicare support ends, and so family members assume financial responsibility for healthcare services as well as contribute their own time to the care of their aging parents (Alzheimer's Association, 2011a; HealthDay, 2012).

In many cases, family caregivers are helping aging adults suffering from some form of cognitive decline and/or dementia. Dementia is on the rise with three and half million people suffering from its deleterious impact (Plassman et al., 2007), and it is ranked fourth among leading causes of death in high-income countries (World Health Organization, 2007). Dementia symptoms include forgetfulness, aggressive behavior changes, sleeplessness, restlessness, confusion, difficulty reading and communicating, poor judgment, social withdrawal, and mental health problems like depression, hallucinations, delusions, and agitation (Alzheimer's Association, 2011a; U.S. National

Library of Medicine, 2012). Researchers have found that family caregivers caring for aging adults with dementia are more likely to report higher stress and burden than other caregivers because of the specific challenges in providing care to this population and coping with its exacerbated symptoms (Alzheimer's Association, 2011a; Bertrand, Fredman, & Saczynski, 2006).

Other researchers have found that family caregivers have felt a lack of social support in the process of caregiving (Adams, 2006; Dilworth-Anderson, Williams, & Gibson, 2002). Researchers differentiated social support from instrumental support, and found the former to be more important to positive outcomes in the caregiving process rather than the latter (Dilworth- Anderson et al., 2002). Yet, caregivers did not feel support and they did not want to ask for it. Adams (2006) found that caregivers not only felt disconnected from needed social support, but also were reluctant to help in more involved ways because of strong desires to maintain things as they always had been. Adams seemed to refer to experiences of multiple caregivers in systems of care and alluded to strong patterns of intercommunication and family roles that maintain rules of engagement in caregiving systems. Thus, family members' roles and channels of communication may have an impact on the experience of social support and felt connection in the caregiving process.

Adams (2006) recommends the presence of a system of caregivers to help in the process of caregiving, which is contrary to the reality of services for and existing literature on primary caregivers. Indeed, family caregivers can be spouses, adult children, other relatives, and perhaps even friends and neighbors (Bertrand et al., 2006; HIP &

NAC, 2005). More than half the time, however, adult children have been caring for these aging adults (NAC, Schulz, & Cook, 2011). In reality, therefore, the system of care may consist primarily of adult siblings who collaborate in the care of their aging parents.

In light of the complex interconnections of the caregiving system, it is important to understand what approaches are being used to assist aging adults and their caregivers in the process, especially related to dementia care. Therefore, it is necessary to examine just what is involved in dementia caregiving and who the caregivers are. Additionally, it is advantageous to make sense of the models used to accommodate adult children who are balancing added responsibilities of caring for aging parents with dementia. The following paragraphs will shed light on how adult parents with dementia are being cared for, who is doing the caregiving, and what models are being used to address challenges of dementia care.

Addressing the Dementia Caregiving System

In modern day American society, people often live busy lives full of various activities and roles. In particular, most adult children of aging parents have moved out the family of origin home, secured their own careers, and started their own families. Many live fast-paced and jam-packed day-to-day lives, with hardly any room for other roles. However, when parents' health begins to decline and they can no longer take care of themselves, their adult children step up to the plate to take over their responsibilities – oftentimes while adult children continue to manage their own individual obligations. To help balance tasks in the system of care, a number of approaches have been developed for aging adults and their caregivers. They include implementation of formal care services,

focus on primary caregiving relationships between care recipients and caregivers, and understanding network models that help define systems of care.

Formal Care for Dementia

One of the main ways that dementia caregiving has been addressed is through the involvement of some type of formal care. Formal caregiving involves securing the physical, mental, and emotional health and wellbeing of aging adults with cognitive decline. People who engage in formal care are direct-care workers and professionals in communities and medical centers that provide a variety of services to care recipients and their families. Assistance may range from helping care recipients with instrumental duties (i.e., cooking, cleaning, running errands, etc.) or with activities of daily living (i.e., bathing, dressing, feeding, etc.; Alzheimer's Association, 2011a; MetLife, 2011; U.S. National Library of Medicine, 2012). Additionally, care services may be focused on residential and/or in-home treatment for care recipients, and/or it may be targeted to helping primary caregivers balance their various obligations (DARTS, 2012; Eldercare Partners, 2012).

In most formal care programs, emphasis is placed on physical and medical management of care recipients' health or on information about dementia's progression. For example, many residential care settings for aging adults with dementia focus their attention on fostering physical safety and security from wandering, accessibility to help with daily care tasks, and monitoring of nutritional and medical needs (Altercare of Ohio, 2012; Grand Assistance 2012; Seniors Guide, 2012; Spectrum Retirement Communities, 2012). On the other hand, when assisting family members of care recipients, formal care

providers focus on provision of service information and education about forms of cognitive decline. For instance, some programs educate about dementia and expected behavior changes that family members with dementia may experience (Altercare of Ohio, 2012; Spectrum Retirement Communities, 2012). Whether it is for the care recipient or the family caregiver, much of formal care support is targeted on physical manifestations of dementia. Thus, focus of formal care is primarily on physical manifestations of dementia and the instrumental support that formal care can provide.

Primary Caregivers

Another major way that dementia caregiving is being addressed is through the relationship between designated primary caregivers and their aging family members. Focus is placed more on connections in this dyadic relationship, and less on the many different family relationships that contribute to systems of dementia care. Although many dementia care programs purport to help both family members and friends of care recipients in various ways (Altercare of Ohio, 2012; DARTS, 2012; Spectrum Retirement Communities, 2012), the research on which many programs base their family information is often from the reports of designated primary caregivers (DARTS, 2012; Matthews & Rosner, 1988).

Considered separately, these reports of primary caregivers of aging parents with dementia have provided a perspective on the intense impact that dementia caregiving can have on balancing life roles. Indeed, researchers have found that dementia caregivers experience burden, loss of control, and lack of social support (Adams, 2006; Alzheimer's Association, 2011a, 2011b; Bertrand et al., 2006; Dilworth-Anderson et al., 2002; NAC

et al., 2011; Pinquart & Sorenson, 2003; Wallhagen & Kagan, 1993; Zarit, Stephens, Townsend, & Greene, 1998). Other researchers, however, have found that in many dementia caregiving systems other types of involvement greatly influence the caregiving process, including routine, backup, circumscribed, sporadic, and dissociative types of caregiving (Matthews & Rosner, 1988; Ingersoll-Dayton, Neal, Ha, & Hammer, 2003). Thus, centering research only on primary caregiver points of view limits the scope of problems involved in caregiving and possible resources that are available within family caregiving systems – resources that formal care may provide at high costs or not provide at all.

Network Model Approach

A third important way that dementia caregiving has been addressed is from a network model theoretical approach. Network models are based on social network research that emphasizes the importance of delineating dyadic relationships between focal individuals and other individuals who make up the network (Cantor, 1991; Kahn & Antonucci, 1981). For example, emphasis is on discovering behavioral links between care recipients and identified caregivers. Beneficially, Cantor's social care model, as well as Kahn and Antonucci's convoys of social support, emphasize that caregiving is within the context of a multi-member system. Thus, interactions of focal individuals with all parties in a network are important. In some cases, however, individuals in systems have more influence than others, and so provide more caregiving tasks. In Sims-Gould and Martin Matthews' (2007) research on assistance to family caregivers, they used Cantor's (1991) and Kahn and Antonucci's (1981) models to understand how family caregivers helped in

caregiving systems. They wanted to understand who helped caregivers, how others helped caregivers, and if others provided direct help to care recipients or assistive help to primary caregivers. Using a combination of network models to understand their results, they found that within family systems caregivers reported many types of caregiving involvement and various kinds of assistance (Sims-Gould & Martin Matthews, 2007). However, their results were based on individual reports of caregiving and assistance to caregivers, and not actual reports from all members of caregiving systems. Additionally, data were collected in mass survey sampling, and not by family units. As a result, their findings did not expose the actual nature of specific family caregiving systems. Instead, data allowed researchers to make observations about generalized roles and frequencies of contributions based on how respondents identified themselves in their caregiving systems. Although network models described observable actions of individual representatives of systems of care, they did not identify patterns of intercommunication that added to development of caregiving roles because they targeted single caregivers from different families.

Limitations to Previous Approaches

Noble efforts have been made by formal and family caregivers to help care for each other and their aging family members with dementia. However, despite good intentions of the aforementioned approaches, family caregivers are still experiencing burden, stress, and lack of social support. It is this researcher's contention that problems stem from the limitations of current approaches in addressing the various factors that influence caregiving systems.

First, formal dementia caregiving overly focuses on the medical approach to maintaining health, and places heavy emphasis on instrumental tasks to support both care recipients and family caregivers. In the literature on dementia caregiving, much attention has been focused on strategies to address care recipient physical and instrumental needs. Formal caregivers emphasize care that maintains physical health and safety of care recipients (Altercare of Ohio, 2012; Grand Assistance 2012; Seniors Guide, 2012; Spectrum Retirement Communities, 2012). Nonetheless, and keeping with one of the top priorities of the Centers for Disease Control and Prevention – maintaining cognitive health (CDC & Merck Company Foundation, 2007) – other researchers have found that formal caregivers’ instrumental support activities do not always fulfill their patients’ emotional and social needs – needs that may contribute to cognitive health (Moyle et al., 2011). Moreover, what seems most important is fostering aging individuals’ sense of meaning and connection to loved ones. Rather than instrumental help, Moyle et al. found that social and emotional supports were more important. This finding is congruent with Cobb’s (1976) model that differentiates instrumental support from social support, and finds that certain types of social support were differentially important to positive outcomes in various populations.

Second, much of the literature that exists is based on research on primary caregivers. Little attention has been paid to various caregivers in dementia care systems and the interdependent communication that fosters or hinders connections and supports needed in the caregiving process. As mentioned above, researchers often use primary caregivers’ reports of their experiences and perceptions to understand caregiving

processes (Ingersoll-Dayton et al., 2003; Matthews & Rosner, 1988; Sims-Gould & Martin Matthews, 2007). Yet, they also have found different types of caregiving involvement exist. Two insights can be drawn from this: (1) if there are different types of involvement than just primary caregiver, then there are different possibilities of caregiver experience and perception; and, (2) if a significant portion of research on family caregivers is based on single caregivers' perspectives, then even research that finds multiple types of involvement is limited by being based only on the point of view of one caregiver in the caregiving system. Thus, research may be biased and reflect only the primary caregiver's point of view.

In addition, different types of caregiving involvement often are divided between siblings in a family. Researchers have found that roles played in the family of origin are maintained by the family system (Hecker, Mims, & Boughner, 2003) and that oftentimes, the same roles are recapitulated later on in the caregiving process (Matthews, 1995; Matthews & Rosner, 1988; Schulman, 1999). Thus, family members designated with "primary caregiver" roles could be continuing similar family roles that they always had, and thus reports of burden, stress, and lack of social support may relate to repeated patterns of communication in the family system, as much as to the added responsibilities of caregiving. Therefore, attention on only primary caregivers not only limits what can be understood about the various types of caregiving involvement, but also it limits the understanding of the influence that interconnections of the sibling caregivers has on the caregiving process.

Third, much of the research on caregiving is concentrated on the incidence and prevalence of caregiving tasks, and very few studies have been based on theoretical models. Those that do, however, use social network models to theorize about caregiving connections in systems of dementia care. The strength in using these models is that they describe the members involved, their relative prominence, and direct and indirect contributions to the system. Yet, network models do not address long-standing patterns of feedback that families have used to maintain their patterns of interaction, and thus preserve family status quo. Hence, a final limitation to previous research is that it has ignored the importance that family system interactions and communication have on systems of care for aging adults with dementia.

Gaps in the Literature

Although the literature on family caregivers is expansive, there is a lack of focus on the interconnections and supports of family members in the care of aging parents with dementia. Research predominantly has examined the instrumental and physical nature of caregiving. Additionally, existing research has focused on primary caregivers, and none of this research has applied a family systems model to understand the dynamics contributing to the experience and perceptions of caregiving for aging adults with dementia. This is surprising in light of the great number of adult siblings who are taking on the responsibilities of caregivers to their aging parents. The problems that caregiving siblings face within the context of caregiving systems – a subsystem of the larger family system – are related to family rules of interaction and communication, in addition to any intrapsychic problems of individual family caregivers. Thus, problems of caregivers are

family system problems. And therein lies the gap in the literature, a paucity of research on adult sibling caregivers in their family system context.

Need for the Study

Stemming from the limitations in previous research as well as gaps in the literature, there is a need to understand family system members who contribute to systems of dementia care, their roles, patterns of communication, and the ways they help each other in the caregiving process. Most often, focus is placed on instrumental supports that can be provided. However, instrumental assistance is not enough. More study is needed to understand the presence of social support and how it manifests in caregiving systems. In our “bottom line” society, it seems that value is only found in those tasks that are measurable and quantifiable. However, family caregivers have a need to feel loved, balanced, and validated in the roles they play – some researchers believe that these feelings may be more important than any other kind of support (Cobb, 1976). Thus, there is a need to understand how social support, separate from instrumental support, emerges in relationships of caregiving siblings.

Additionally, there is a need to focus on sibling caregivers’ relationships, family roles, and responsibilities that contribute to their experiences and perceptions of sibling connection in caregiving processes. In many cases, caregivers are cutting their work schedules, giving up their personal time, and trying to balance their lives with responsibilities of caregiving to their aging parents with dementia. As will be seen, connections that are experienced between siblings are crucial to understanding various sacrifices siblings make, as well as their chosen level of caregiving involvement. What

researchers have found is that oftentimes those roles played in the family of origin are repeated in the caregiving relationship (Matthews, 1995; Matthews, Adamek, & Dunkle, 1993; Matthews & Rosner, 1988; Schulman, 1999). Therefore, determining the nature of connection between siblings and the roles they played may be important to understanding their contributions to the caregiving system.

Finally, there is a need to uncover feedback structures that contribute to patterns of family members' interactions in dementia caregiving systems. In family systems theory, there are two main forms of feedback between members of systems: 1) feedback that rejects change and maintains family status quo, and 2) feedback that accepts change and assimilates to a new way of doing things for the good of systems (Hecker et al., 2003). In dementia caregiving systems, both forms of feedback may be at work to maintain equilibrium. Feedback between adult siblings may work to maintain certain roles and expectations of contributions to caregiving process – possibly ways that have always been stressful, but have become the status quo of the family. On the other hand, feedback may work to create change in the structure of how things are handled, so that siblings who were always “in charge” when growing up, but who presently live out-of-town, take on alternative types of caregiving involvement and contribute in equitable ways through social and emotional support to both their parents and their caregiving siblings. From a family systems theoretical perspective, primary care providers' problems exist within interconnections between family members that are part of the system of care. Therefore, in order to understand and help these family caregivers it is essential to understand their concerns from the point of view of the whole family.

Statement of the Problem

The problem is threefold: 1) there is a growing population of aging parents with dementia and subsequent obligation of adult children to care for parents; 2) models that exist do not address unique caregiving sibling connections in caregiving systems; and 3) models that exist do not focus on social support that is perceived and experienced between caregiving siblings in systems of care for aging parents with dementia. Because of the over-reliance on primary caregiver perceptions and experiences, the interdependent and contextual factors, and their influence on caregiving sibling systems, get missed. Additionally, by broadly exploring all supports from network model approaches, researchers and clinicians may not fully understand the definitive importance of caregiving sibling social support – which is based on family of origin expectations for filial care, roles, and structure that dictate how adult children will care for their aging parents. Moreover, caregiving siblings may be at heightened risks related to low social support because of the different challenges that are involved in caring for parents with forms of dementia.

Purpose of the Study

The purpose of this study was to explore perceptions and experiences of sibling connection and social support between siblings caring for aging parents with dementia. The study had three main objectives. The first was to explore perceptions and experiences of sibling connection in order to understand differential circumstances that siblings had while caring for parents with dementia. The second was to investigate the degree of social support related to dementia caregiving processes that was perceived and

experienced between siblings. The third was to understand emergent themes that clarified dementia caregiving in family systems.

Research Questions

There is a gap in the literature on caregiving. It is unknown what phenomena of caregiving sibling systems affect perceptions and experiences of sibling connection and social support (or lack of sibling connection and social support), especially with regard to intense tasks of caring for parents with dementia. Accordingly, there were three research questions in this study:

- 1) What phenomena emerge that clarify caregiving siblings' perceptions and experiences of sibling connection in dementia care?
- 2) What phenomena emerge that clarify caregiving siblings' perceptions and experiences of social support in dementia care?
- 3) What themes emerge that clarify the dementia caregiving system for adult sibling caregivers?

Definitions of Terms

In reviewing the literature, many specific terms were found to differentiate states of cognitive health and decline, and various types of caregiving support, connection, and involvement have been discovered. The following list defines terms most essential to understanding the experiences and perceptions of caregiving siblings of parents with dementia:

Cognitive health is the “combination of mental processes we commonly think of as ‘knowing’ and includes the ability to learn new things, intuition, judgment, language, and remembering” (CDC & Merck Company Foundation, 2007; p. 5).

Mild cognitive impairment occurs when individuals have difficulties with thinking and memory that do not interfere with daily living (U.S. National Library of Medicine, 2012). Symptoms may include difficulties multitasking, problem solving, decision-making, remembering recent events, and taking more time than usual. However, they do not significantly inhibit day-to-day functioning (Alzheimer’s Association, 2011a).

Dementia can be broadly defined as loss of brain functioning that affects memory, thinking, communication, judgment, and behavior (U.S. National Library of Medicine, 2012). It can take the form of degenerative (Alzheimer’s Disease), vascular, lewy body, or be related to other health conditions and preventable behaviors (Alzheimer’s Association, 2011a; American Psychiatric Association, 2013). Additionally, its symptoms can range from mild impairment, like forgetfulness, to severe symptoms like difficulty remembering and recognizing family members and incontinence and swallowing problems (Alzheimer’s Association, 2011a; U.S. National Library of Medicine, 2012).

Activities of Daily Living (ADL) include care and maintenance of personal needs of care recipients like dressing self, bathing, walking, feeding self, using the toilet, and getting into bed (Alzheimer’s Association, 2011a; MetLife, 2011; U.S. National Library of Medicine, 2012).

Instrumental Activities of Daily Living include providing indirect support to the care recipient, including preparing meals, transportation, errands, yard work, and household chores (Alzheimer's Association, 2011a; MetLife, 2011).

Care recipients are aging adults who have levels of cognitive and physical decline that have caused them to rely on the help of others for their instrumental activities of daily living and their personal activities of daily living. They may not be formally diagnosed with forms of dementia, but spouses or adult children may initially witness changes in care recipients' personalities, behaviors, and abilities to remember (HIP & NAC, 2005; U.S. National Library of Medicine, 2012). Additionally, care recipients may require temporary, short-term, or long-term care.

Caregiving is defined as the emotional, social, or behavioral tasks of providing assistance to an aging parent that has been suspected of having or diagnosed with some form of dementia. In the context of caring for aging parents, caregiving might include emotionally consoling parents who have lost a spouse or a friend, providing assistance with activities of daily living, or taking responsibility over legal, financial, and health decisions for parents with dementia. More specifically, caregiving may consist of five main styles of caregiving sibling involvement, as described by Matthews and Rosner (1988). They include: 1) Routine caregiving – parental caregiving tasks were incorporated into siblings' daily lives, 2) Backup caregiving – siblings would make themselves present to support siblings who were routinely involved, and could be counted on to follow orders, 3) Circumscribed caregiving – siblings who were predictable in being able to help, but who had boundaries on what they could help with, 4) Sporadic

caregiving – siblings who would become involved at their own convenience, and 5) Dissociation in caregiving – siblings who were predictable in not being involved or counted on to help (Matthews & Rosner, 1988).

Formal caregivers can be defined as direct-care workers and professionals in communities and medical centers that have received some form of training to provide a range of services to care recipients and their families, from phone consultations to residential 24-hour assistance with instrumental and personal activities of daily living. Settings may include assisted living facilities, nursing, personal, care, and adult foster care homes (Alzheimer's Association, 2011a; Quinn, Johnson, Andress, & McGinnis, 2003). Additionally, these settings include agencies and centers that provide consultation to families, help with running errands for care recipients, and/or in-home services (DARTS, 2012; Eldercare Partners, 2012).

Informal caregivers or family caregivers can be defined as family members and/or close friends who are responsible for the daily needs of other individuals, typically without being paid (Bertrand et al., 2006; HIP & NAC, 2005). “Family caregivers are responsible for the physical, emotional, and often financial support of another person who is unable to care for him/herself due to illness, injury or disability” (HIP & NAC, 2005; p. 10).

Caregiving sibling is defined as every child (full biological, half biological, step, and adopted) of the aging parent with dementia, and may include siblings that self-describe their involvement as representative of any of Matthew's and Rosner's (1988) aforementioned styles of caregiving involvement.

Caregiving sibling system is defined as the interdependent and synergistic network of all sibling members – grown children – of the aging parents with dementia. It represents a subsystem of the greater family system, and operates through the function of family systems' mechanisms of positive and negative feedback to maintain equilibrium in the caregiving system.

Sibling connection is the degree of emotional and mental closeness, regardless of physical proximity, that siblings have with each other, determined by the influence of family expectations, roles played in the family of origin, sibling caregiver factors, and sibling caregiving involvement type.

Social support is defined as the presence of mutually respectful, meaningful, and genuine interconnection, assistance, and validation as indicative of three main components: 1) emotional support, 2) esteem support, and 3) network support (Cobb, 1976; House, 1985). In the current study, the component of *emotional support* will be defined as information leading caregiving siblings to believe that they are cared for, loved, trusted, and heard or understood (Cobb, 1976; House, 1985). The component of *esteem support* will be defined as information leading caregiving siblings to believe that they are esteemed and valued, affirmed, and validated in their caregiving approach and in their personal importance to the caregiving sibling system of care to aging parents with dementia. The component of *network support* will be defined as information leading caregiving siblings to believe that they belong to a network of communication, mutual obligation, and where they can get suggestions and directive information about how to care for their parents with dementia, and care for each other in the process.

Instrumental support is defined as the observable assistance given or received in the way of goods, services, or monetary types of help. It may also include labor and/or time (House, 1985).

Caregiving sibling perception is defined as the thoughts and emotions about the presence or absence of sibling connection, social support, and emergent phenomena in the caregiving sibling system as related to instances and circumstances of caring for their aging parents with dementia.

Caregiving sibling experience is defined as the actions that are present with regard to siblings' perceptions of sibling connection, social support, and emergent phenomena among caregiving siblings, on both the part of the responding sibling and the siblings involved with the situation or circumstance.

Organization of Study

This dissertation is presented in five chapters. This first chapter provided an overview of the research on aging adults and approaches to working in dementia caregiving systems. It discussed roles, connections, and supports of adult siblings in systems of care. Additionally, it covered the limitations to current approaches, gaps in the literature, the need for the proposed study to expand this research to a family system perspective (as opposed from primary caregiver focus), stated the purpose and research questions, and defined terms. The second chapter will give a detailed review of literature related to topics of dementia, dementia caregiving, sibling connection, and social support, and further elaborates the need for the proposed study in community counseling. The third chapter will describe the methods that will be used to collect data on caregiving

siblings' perceptions and experiences of social support as related to the care they provide their aging parents with dementia, as well as information about participants and limitations of the study. The fourth chapter will present results of the study. In the fifth chapter, discussion of results, implications for research and intervention, and steps for future research will be discussed.

CHAPTER II

LITERATURE REVIEW

Caring for aging adults with cognitive decline is an important issue that families and communities face in today's world. As individuals get older, they may find themselves naturally moving slower than usual, forgetting day-to-day tasks, and witnessing the weathering impact that years of living puts on their physical and mental beings. As a result, aging adults require their families and communities to help care for them in the ways that they can no longer do on their own. As will be described in the paragraphs ahead, most aging adults and their families agree that primary care should be the responsibility of their adult children (Kahn & Bank, 1981; Ingersoll-Dayton, Neal, Ha, & Hammer, 2003; Matthews, 1995; Matthews, Adamek, & Dunkle, 1993; Matthews & Rosner, 1988; Rosenthal, Martin-Matthews, & Matthews, 1996). However, adult children who must take on primary care duties often have feelings of being overwhelmed, lacking a sense of control, and burdened by tasks (Adams, 2006; Russo, 2010a). Further exacerbating the myriad of caretaking duties is the intensity of responsibility when caring for aging adults with forms of dementia. The kinds of obligations and amount of time that is spent caring for parents with dementia leads many caregivers to feel higher levels of stress and more role captivity as caregivers (Adams, 2006; Bertrand, Fredman, & Saczynski, 2006).

Programs have been developed for assisted living and residential treatment of aging adults with dementia, and some even offer costly services to primary caregivers. Most programs provide assistance through instrumental support, and only bestow social support at a heavy price or indirectly through referrals to support groups. Still, there are no standards or protocols established to help with the complicated list of issues that adult children face in caring for their parents with dementia (Russo, 2010a). Moreover, there is insufficient research on the nature of caregiving from the perspective of the family system, resulting in limited information on the special impact that sibling connection and social support have on caregiving. Because care of aging parents with dementia is a family concern, it is essential to understand the complexities of caregiving for aging parents with dementia from the perspective of the family system (Matthews & Rosner, 1988; Ingersoll-Dayton, Neal, Ha, & Hammer, 2003; Russo, 2010a).

In the following paragraphs, issues of caring for aging adults from the perspective of the family system are discussed. The discourse begins with a broad discussion of aging in the United States (U.S.; with specific focus on the impact of forms of dementia), including its costs to formal and informal caregivers. Next, dementia is defined and described to establish a picture of impact. Then, caregiving, with particular focus on dementia care, is discussed from both formal and informal viewpoints. Once the broad perspective of dementia caregiving is established, the important nuances of adult children caring for aging parents will be presented. Following that will be a discussion of general and adult sibling connections to establish the link between caregiving, sibling relationships, and social support. Finally, the importance of examining sibling

connections and social support of those adult siblings caregivers within the family system context will be presented. To start though, it is necessary to understand general concerns related to aging in the U.S.

Aging

The number of older adults in the U.S. is growing. The population of people age 65 and older is predicted to double in the next 20 years, with an estimated 70 million people age 65 and older making up 20% of the U.S. citizenry (CDC & the Merck Company Foundation, 2007). This dramatic population shift is due to increased life expectancy, as well as the large number of individuals born in the Baby Boomer generation getting older (CDC & the Merck Company Foundation, 2007).

Escalating numbers of aging adults also brings increases in incidents of chronic diseases and degenerative illnesses. In fact, about 80% of aging adults are living with at least one chronic condition and half of adults age 65 and older have at least two (CDC & the Merck Company Foundation, 2007). For high-income countries, degenerative conditions of dementia and Alzheimer's Disease (AD) rank fourth as causes of death (WHO, 2012).

General Concerns

As indicated above, countrywide, health-related causes of death have moved from infectious diseases and acute illnesses to chronic diseases and degenerative illnesses (CDC & the Merck Company Foundation, 2007). Consequently, the types of healthcare and support needed by older individuals have changed from brief remedial care to improvement in the quality of life as they progress into older ages. The CDC and the

Merck Company Foundation suggests that the three most important areas that older adults need to address in the next 20 years include 1) preventing falls, 2) preserving cognitive health, and 3) enhancing end-of-life care. Because of advancements in individuals' physical health, people are living independently and for extended periods of time. Consequently, being able to manage their quality of life by hindering falls and fostering lucid cognition become important factors that will help them, theoretically, live hardily in their *third age* (Westerhof, 2010).

Costs of Aging

In addition to health concerns the cost to support aging adults is significant. The CDC and the Merck Company Foundation (2007) reported that the healthcare cost for individuals age 65 and older is five times the cost of younger individuals. The estimated national cost for all forms of elder care is \$306 billion annually (Eldercare Partners, 2011). The cost to provide health care to aging adults with forms of dementia, however, is three times that of other aging adults. In 2004, the cost to care for an individual with dementia was \$42, 072 compared to \$13,515 for an individual without complications coming from dementia (Alzheimer's Association, 2011a). Moreover, healthcare costs have continued to rise significantly.

For dementia patients, the breakdown of costs paid by formal and informal caregivers is momentous. In general, Medicare and Medicaid pay for about 70% of the costs (specifically the medical costs) to care for aging adults with dementia (Alzheimers.gov, 2013; Alzheimer's Association, 2011a). Total costs spent on formal dementia care for aging adults is estimated to be \$183 billion dollars per year – and

rising. On the other hand, total costs of unpaid care provided by family caregivers are estimated to be \$203 billion dollars annually (Alzheimer's Association, 2011a; HealthDay, 2012).

Estimates of caregiving costs for aging adults are based on the number of services that aging adults with chronic and degenerative diseases may need. With specific focus on dementia care, most costs paid by formal entities, like Medicare and Medicaid, are for services provided by hospitals, skilled nursing facilities, and home health care (Alzheimers.gov, 2013; Alzheimer's Association, 2011a).

There are expenses, however, that formal care will not pay, and these costs are often passed on to dementia patients and their families. In 2004, aging adults with dementia took on an average annual out-of-pocket cost totaling \$3,141 for long-term services that were not covered by other sources (Alzheimer's Association, 2011a). Dementia patients who received services in nursing homes or assisted living facilities incurred average out-of-pocket costs of \$21,272. The troubling concern is that 57% of aging adults in the general community and 75% of aging adults who were in high need for nursing home care do not have the assets to pay for these services. As a result, family members make up for the unpaid care to aging adults with dementia.

Addressing Aging Through Collaboration

It has been acknowledged that to meet the costs and needs of aging adults, especially those with forms of dementia, collaboration is key. Researchers have noted that improvement in the health of aging adults (e.g., those adults 65 years of age and older) will depend on the collaboration of many different sectors of society, community,

and family groups, including national, state, and local sectors, and individuals from government agencies, health care providers, and community groups (CDC & the Merck Company Foundation, 2007; Flaskerud, 2009). Little mention is made, however, of the importance of finding solutions within the families that take on the unpaid informal care of aging adults. The expectation is clearly stated, however, that in cases where formal institutions will not pay for the care of aging adults with forms of dementia, family members often incur the costs and bear the burdens. Given the expectation that family members will play a significant role in bearing the responsibilities of caregiving, examining the family system to understand better their responses to financial and caregiving burdens seems a logical step towards addressing the concerns and needs of these caregivers. However, in order to understand the kinds of resources that families need to care for aging adults/parents with dementia, it is important to understand what dementia is and what the experience is like for care recipients and caregivers.

Dementia

Three and a half million people are living with dementia in the U.S., according to the most recent prevalence ratings (Plassman et al., 2007). Almost 70% of all dementia patients are suffering the effects of Alzheimer's Disease (AD), the most frequently occurring form of dementia (Alzheimer's Association, 2011a; Plassman et al., 2007). With increasing age, the percentage of AD type dementia goes up to 80% of total dementia incidences (Plassman et al., 2007). The prevalence of AD amounts to one in eight aging adults having this form of dementia (Alzheimer's Association, 2011a). About 12 percent of individuals, age 65 and older, have been diagnosed with this disease, and

almost half of adults age 85 and older have it. After being diagnosed, aging adults live an average of four to eight years, but some may live up to twenty (Alzheimer's Association, 2011a).

Differences have been found in the prevalence of forms of dementia by age, gender, education, race/ethnicity, and education. Predictably, the longer someone lives, the more likely it is that they suffer from some form of dementia. Researchers from the Alzheimer's Association found that on average, there are about 53 new cases per 1,000 people with dementia each year in adults age 65 to 74, compared with about 175 new cases per 1,000 people in adults age 75 to 84, and 231 new cases per 1,000 people in adults age 85 and older (Alzheimer's Association, 2011a). Moreover, the annual number of new cases of dementia is predicted to double by the year 2050.

In regard to other demographics, two thirds of individuals with AD are women, which might be related to the tendency for women to live longer than men (Alzheimer's Association, 2011a). Also, researchers found that older African American and Hispanic adults were more likely to develop dementia (Alzheimer's Association, 2011a; Rocca et al., 2011). However, the differences by race and ethnicity may be more likely related to differences in health conditions, education, and socioeconomic status, than to differences specifically related to race or ethnicity (Alzheimer's Association, 2011a; Plassman et al., 2007). With regard to education, individuals with fewer years of education have been found to be at greater risk of developing dementia, which seems to be connected to the level of cognitive reserves that aging adults have developed (Alzheimer's Association, 2011a; Plassman et al., 2007). Cognitive reserves have been defined as those abilities that

allow individuals to compensate for changes in their brains (Alzheimer's Association, 2011a; Rocca et al., 2011).

Even the various differences among aging adults with dementia seem to have more to do with a combination of life circumstances rather than the challenges of specific groups. The important point is that cognitive decline is a condition that impacts many different aging adults and their families. To better understand the impact of dementia on the family unit, it is necessary to understand the nature of the disease itself.

Dementia Defined

There are a number of terms used to describe forms of cognitive health and cognitive decline. To begin with, cognitive health is a term used to define the state of optimal and independent brain functioning. The CDC and the Merck Company Foundation (2007) define cognitive health as the “combination of mental processes we commonly think of as ‘knowing’ and includes the ability to learn new things, intuition, judgment, language, and remembering” (p. 5). Therefore, maintaining cognitive health is important for individuals to be able to think coherently and make decisions independently.

The opposite of cognitive health are terms used to define forms of cognitive decline, including mild cognitive impairment and forms of dementia. Mild cognitive impairment is when individuals have difficulties with thinking and memory that do not interfere with daily living (U.S. National Library of Medicine, 2012). Symptoms may include difficulties in multitasking, problem solving, decision-making, remembering recent events, and taking more time than usual to perform tasks. Although symptoms may

be severe enough that they are noticeable to others, they do not significantly inhibit day-to-day functioning (Alzheimer's Association, 2011a).

When symptoms of forgetting and confusion begin to affect multiple facets of living, it usually signals the onset of forms of dementia. Generally, dementia can be defined as loss of brain functioning that affects memory, thinking, communication, judgment, and behavior (U.S. National Library of Medicine, 2012). Psychologically speaking, the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision* (American Psychiatric Association, 2000) defines specific criteria that must be met in order to differentiate dementia symptoms from delirium (an acute confusion state). For a diagnosis of dementia, individuals must experience memory loss and decline in at least one area of functioning, including speech and understanding language, recognition and identification of objects, motor activity, thinking abstractly and making decisions. In addition, symptoms must interfere with multiple areas of daily life. The problem is that some presentations of delirium may have similar features to dementia. *The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition*, moves closer to clarification of delirium as acquired cognitive impairment that has an acute onset and temporal course, since a majority of individuals make a full recovery (American Psychiatric Association, 2013). On the other hand, dementia is defined as an acquired major neurocognitive disorder with variable etiology and course of development depending on the specific type (e.g., Alzheimer's disease, Vascular disease, Lewy body disease, traumatic brain injury).

From a medical point of view, the Alzheimer's Association (2011a) broadly describes dementia as a condition in which brain cell connections become damaged so that they can no longer provide and receive feedback between cells and can no longer take in and use nutrients for energy production within the brain cells. Furthermore, it underscores that the occurrence of forms of dementia, including AD, is not a normal symptom of aging. Rather, it is a symptom of abnormal physiological changes in the brain (Alzheimer's Association, 2011a). Consequently, aging adults who are developing forms of dementia, as well as their adult children who care for them, will have to deal with self-care and caregiving duties that are not typical of normal aging.

Two other phrases that are frequently used when discussing dementia, its impact, and the responsibilities involved are *activities of daily living* and *instrumental activities of daily living*. Activities of Daily Living (ADLs) are those that include the care and maintenance of personal needs including dressing self, bathing, walking, feeding self, getting into bed, and using the toilet, as well as avoiding unsafe activities, like wandering (Alzheimer's Association, 2011a; MetLife, 2011; U.S. National Library of Medicine, 2012). On the other hand, Instrumental Activities of Daily Living (IADL) are activities that include the care and maintenance of daily living activities such as preparing meals, driving and using other transportation, completing household chores, doing yard work, going grocery shopping and running errands, taking medications and following medical treatment recommendations (Alzheimer's Association, 2011a; MetLife, 2011). In reading the literature on dementia, these two terms (ADL and IADL) seem to get used interchangeably in some cases, differentiated in others. However, the distinction seems

particularly important in that it helps clarify the types and features of dementia symptoms and specific care that must be given to individuals with dementia.

Dementia Types, Features, and Course

To the general public, dementia for one person may look like dementia for all. Certainly there are a number of basic features, like general forgetfulness and confusion in different areas of individuals' lives. However, there are many different types of dementia with varying features and courses of progression. The reasons why different forms of dementia develop are not known. Still, researchers suggest that it most likely occurs as a result of many different factors, rather than just one cause (Alzheimer's Association, 2011a; American Psychiatric Association, 2013). Understanding of the different types, features, and course of dementia can provide care recipients and their caregivers with good starting places from which to manage treatment.

Researchers have found six main forms of dementia. The first, and most common, is degenerative dementia ((Alzheimer's Association, 2011a; U.S. National Library of Medicine, 2012). This form of dementia is caused by a build up of plaque (protein fragment beta-amyloid) at brain cell synapses and outside of the brain cells, as well as a build up of tangles of proteins (twisted strands of protein tau) within brain cells (Alzheimer's Association, 2011a). The most common form of degenerative dementia is AD, accounting for 60-80% of dementia cases (Alzheimer's Association, 2011a; American Psychiatric Association, 2013; Plassman et al., 2007; U.S. National Library of Medicine, 2012). Early symptoms include memory loss, apathy, and depression. Later symptoms may appear as problems with judgment, disorientation and confusion, changes

in behavior, and problems with walking, speaking, and swallowing (Alzheimer's Association, 2011a).

The second most common type of dementia is vascular dementia. This form of the disease is caused by interrupted blood flow to the brain, often occurring from small strokes that block arteries (Alzheimer's Association, 2011a; American Psychiatric Association, 2013; Erkinjuntti, 2005; U.S. National Library of Medicine, 2012). In vascular dementia, memory may not be as seriously affected as it is with Alzheimer's related dementia, but it overlaps with the other symptoms of degenerative types of dementia (Alzheimer's Association, 2011a; Roman et al., 2004).

The third most common type of dementia is caused by an abnormal build up of lewy bodies (strands of protein alpha-synuclein) within the nerve cells of the brain (Alzheimer's Association, 2011a; American Psychiatric Association, 2013). Early symptoms include decline in memory, judgment, and behavior. Later symptoms include problems with alertness, visual hallucinations, muscle rigidity, tremors, and daily fluctuations in cognitive symptoms (Alzheimer's Association, 2011a).

The fourth most common type of dementia is caused by preexisting conditions, such as Huntington's disease, multiple sclerosis, HIV/AIDS, Lyme disease, Parkinson's disease, Pick's disease, Creutzfeldt-Jakob disease, and Progressive Supranuclear Palsy (Alzheimer's Association, 2011a; American Psychiatric Association, 2013; U.S. National Library of Medicine, 2012). In these diseases, loss of memory and decline of adaptive nervous system functioning are the most common symptoms. However, in the preexisting condition of normal pressure hydrocephalus, the fifth type of dementia, cognitive loss is

caused by a build up of fluid in the brain (Alzheimer's Association, 2011a). Symptoms include loss of memory and difficulties walking and controlling urination. Still, dementia symptoms may be remedied by surgically installing a shunt in the brain to drain the build up of fluid.

The sixth most common type of dementia is caused by preventable behaviors, such as brain injuries, brain tumors, chronic alcohol abuse, metabolic changes in blood sugar, sodium, and calcium levels, low vitamin B12 levels, and certain medications (Alzheimer's Association, 2011a; U.S. National Library of Medicine, 2012). Other conditions related to the development of dementia include high blood pressure, elevated cholesterol, diabetes, overweight and obesity, smoking, and physical inactivity. Contrary to the course of other forms, dementia caused by preventable behaviors can be thwarted through living healthy lifestyles focused on holistic wellness.

The reason why dementia begins to take its course is not clearly known. However, researchers have found that excess proteins form in brain cells, which damage them and inhibit them from communicating with other cells. This damage causes a breakdown in affected areas, such as memory and judgment, and manifests as changes in behaviors, as mentioned above (Alzheimer's Association, 2011a). Often, individuals have more than one type of dementia. Because protein build up interferes with the transfer of information and nutrients between and within cells, brain cells eventually die (p. 8). In all types, dementia eventually impacts all parts of individuals' mind-body functions.

Dementia Symptoms

Although symptoms of dementia present in most areas of life for aging adults suffering from this condition, these symptoms may vary in levels of intensity. In general, dementia symptoms can be categorized as mild, moderate, or severe. Mild symptoms are those that interfere with daily living, but that still allow aging adults to function independently (Alzheimer's Association, 2011a; U.S. National Library of Medicine, 2012). The most notable sign of the beginnings of dementia is decreased memory, first appearing as forgetfulness. Subsequent symptoms include: difficulty with language and communication; challenges with perception and understanding; changes in emotional expression and behavior or personality; decline in cognitive skills of abstract thinking, judgment, and activities that take more thought, like calculating and planning; and difficulty in performing tasks that used to be easy or learning new things (Alzheimer's Association, 2011a). In addition, other, milder symptoms might include getting lost in familiar places, misplacing things, or losing interest in things that used to be enjoyable (U.S. National Library of Medicine, 2012).

Moderate symptoms of dementia are those that interfere with independent living (U.S. National Library of Medicine, 2012). These kinds of symptoms include the experience of sleeplessness and restlessness; difficulty performing IADLs; forgetting details of current events and life history; and exhibiting behavior changes including arguments, striking out, and violent behavior (U.S. National Library of Medicine, 2012). Additionally, aging adults with moderate dementia might experience mental health concerns including hallucinations, delusions, depression, and agitation; confusion with

time or place; difficulty in reading and writing and communicating with words; poor judgment and inability to differentiate safely; and social withdrawal (Alzheimer's Association, 2011a; U.S. National Library of Medicine, 2012).

Severe symptoms are those where aging adults with dementia can no longer independently care for themselves (U.S. National Library of Medicine, 2012). Individuals with severe symptoms have difficulty performing ADLs; problems remembering and recognizing family members; decreased understanding; trouble with comprehending visual images and spatial relationships; and incontinence and swallowing problems (Alzheimer's Association, 2011a; U.S. National Library of Medicine, 2012). In addition, Sink, Covinsky, Newcomer, and Yaffe, (2004) found that symptoms that caused particular stress and strain to both care recipients and caregivers were persistent restlessness and talkativeness, having hallucinations, experiencing paranoia, presenting unreasonable anger and combativeness, wandering, and waking the caregiver. Moreover, severe stages of dementia are ultimately fatal, with related pneumonia being the primary cause of death (Alzheimer's Association, 2011a).

As can be seen, categories for mild versus moderate or severe levels of dementia are not necessarily mutually exclusive. Depending on individuals' particular experience, they may have any number or combination of the aforementioned symptoms.

Additionally, depending on the perceptions of the caregivers involved, family members might experience symptoms labeled mild as intensely severe, and those labeled severe as moderate or mild. Indeed, researchers have found links between caregiver characteristics and perceived dementia symptoms in care recipients (Sink et al., 2006; Volicer, Hurley,

& Blasi, 2003). In any case, treatment for particular types of dementia with different levels of symptoms can enhance the quality of life for care recipients and their caregivers (Alzheimer's Association, 2011a; CDC & the Merck Company Foundation, 2007; National Institute of Neurological Disorders and Stroke, 2013a).

Dementia Treatment

When individuals' cognitive decline progresses to forms of dementia, goals of treatment turn towards improving end of life care. Because of the various types of dementia and presenting symptoms, there are several courses of action that individuals with forms of dementia can take to improve their quality of life. However, with regard to the two most common forms of dementia, degenerative and vascular, there are no treatments known to cure or slow down their effects (Alzheimer's Association, 2011a; National Institute of Neurological Disorders and Stroke, 2013b). Still, aging adults with dementia may benefit from end of life care that manages their medical, daily living, and overall quality of life needs.

Medical management of aging adults with dementia involves assessing what their needs are, making decisions about potential plans of action, and active engagement in appropriate treatment options (Alzheimer's Association, 2011a). For example, medical management may consist of integrating co-existing conditions in treatment planning, coordinating care among formal and informal caregivers, and using supportive services, activity groups, adult day care, and counseling (Alzheimer's Association, 2011a). In addition, individuals with dementia might benefit from medication maintenance as part of their medical management plan. Typically, the maintenance of medication includes

stopping or changing medications that heighten confusion or limit brain functioning (Alzheimer's Association, 2011a; National Institute of Neurological Disorders and Stroke, 2013b). Also, some medications may be prescribed specifically to help control behavior concerns. Although there are medications that may slow or stop the progression of some forms of dementia (in some cases for a duration of only six to 12 months) these medications are only effective in 50% of individuals who use them (Alzheimer's Association, 2011a).

Another treatment approach is to encourage the modification of lifestyle preferences of aging adults with dementia. In particular, the Alzheimer's Association (2011a) recommends changing to a vegetarian and low-fat diet to mitigate problems or even prevent the occurrence of symptoms. In addition, regular exercise and participation in mental activity may slow cognitive decline (Alzheimer's Association, 2011a; Moyle et al., 2011; Whitehouse, 2008).

Most treatment is focused, however, on fostering quality of life in aging adults with dementia for their physical experience, as well as their cognitive functioning. As will be presented in subsequent sections, both formal and informal caregivers support quality of life by ensuring safe and comfortable surroundings in which aging adults' IADLs and ADLs are met (Altercare of Ohio, 2012; DARTS, 2012; Grand Assistance, 2012; Seniors Guide, 2012; Spectrum Retirement Communities, 2012). Additionally, formal care services frequently provide some form of social connection, both in-home and in residential services. Some researchers suggest that engagement in social activities and meaning-making experiences may be crucial to psychological well being. For

example, Moyle et al. (2011) found that family was considered to be pivotal to the well being of aging adults with dementia. When they asked residents in a dementia care facility about the importance of family in maintaining quality of life, residents reported that “although visitors were important, in particular as a means of relieving boredom and loneliness, unless the visitor had known the resident pre-dementia, the conversation between the visitor and resident was limited” and thus, unmeaningful (Moyle et al., 2011; p. 974). Furthermore, these researchers reported that staff instrumental support activities did not fulfill their patients’ emotional and social needs, highlighting the importance of social support over instrumental support.

Limitations of the Moyle et al. (2011) study were its small convenience sample, as well as inability to generalize findings because of its qualitative approach. A crucial point, however, is that researchers included sub-concepts of close family members and friends into the general concept of family. Therefore, discerning actual family support from friend support could not be determined. Still, the suggestions that quality of life for aging adults with dementia may depend on the social connections and support that is perceived between care recipients and their family is important to understanding the dynamic family system that fosters the network of care and treatment for aging adults with dementia.

All in all, interventions that target end-of-life care, emphasize the management of dementia, and foster collaboration between formal and informal caregivers are typical of how aging adults with dementia are receiving treatment. In all approaches, focus is placed on upholding individuals’ quality of life. However, what seems particularly

important is the fostering of individuals' sense of meaning and connection to loved ones. Interestingly enough Moyle et al. (2011) found that it was the involvement of family members in aging adults' care, as well as the personal connection that they shared, that seemed to improve their quality of life. Yet, much of the literature focuses on the importance of attending to aging adults' IADLs and ADLs. Further, the research overly focuses on burden that primary caregivers feel in providing for aging adults with dementia. To date, minimal literature has discussed relationships between care recipients and their family caregivers, relative to personal connection and social support. Moreover, no research has focused on the many different caregivers involved in caregiving. Nor has research examined connections and social support that are experienced between family caregivers – who often are adult siblings sharing in the treatment and management for their aging parents with dementia. Perhaps it is a culmination of care recipients' symptoms, level of intensity, and proposed treatment planning with formal and informal caregivers that becomes a complicated web to untangle.

Dementia Risk Factors

There are a number of factors that put aging adults at-risk for developing dementia. First, as individuals age, the likelihood of developing dementia increases (U.S. National Library of Medicine, 2012). Most aging adults who develop dementia are age 65 and older, which is considered late-onset dementia. However, it may occur in individuals who are younger as a result of familial heredity or early-onset dementia (Alzheimer's Association, 2011a).

In addition, family history can put aging adults at risk for developing dementia. In particular, individuals with a first degree relative with dementia are more likely to develop the disease (Alzheimer's Association, 2011a; Whitehouse, 2008). Further, the likelihood increases if aging adults have more than one relative with dementia. Although the connection may be related to genetic heritability, environmental factors also may play a role (Alzheimer's Association, 2011a; National Institute of Neurological Disorders and Stroke, 2013b; Whitehouse, 2008).

With regard to genetic heritability, researchers have found a relationship between the presence of a cholesterol gene in individuals' DNA and the occurrence of dementia. Individuals who inherit the APOE gene are at increased risk of Alzheimer's related dementia (Alzheimer's Association, 2011a; Laws et al., 1999; Whitehouse, 2008). The APOE gene is the blueprint for the protein that carries cholesterol in the blood. There seems to be a connection between the proteins that the APOE gene creates and the excess formation of proteins in the brain cells of individuals with dementia (Laws et al., 1999). Furthermore, excess protein formation in brain cells causes degenerative and vascular types of dementia – the two most common forms of the disease (Alzheimer's Association, 2011a; Smith et al., 1991). Perhaps there is a link between processing of cholesterol in the body and the formation of dementia – a relationship that may be predicted, and thus, one that could be planned for. Possibly, families of aging adults with dementia could come together to bolster cognitive health and psychological wellbeing (Moyle et al., 2011), and maybe prevent or slow the process of dementia.

Other risk factors present themselves as part of preexisting conditions. As mentioned previously, there are a number of diseases and disorders that may lead to the breakdown of brain cell function and therefore lead to symptoms of dementia. However, two conditions not mentioned that may or may not lead to dementia are mild cognitive impairment (MCI) and cardiovascular disease. MCI primarily presents symptoms of memory and decision-making problems that do not interfere with daily tasks. It is estimated that between 10 and 20 percent of aging adults have forms of MCI, and 15% of those individuals with it end up developing dementia each year (Alzheimer's Association, 2011a). Yet, when coupled with a number of other risk factors, the risk may multiply (Plassman et al., 2011).

Cardiovascular disease is another preexisting condition that may relate to the formation of dementia. Brain health is dependent on the health of the cardiovascular system, including the blood vessels and heart (Alzheimer's Association, 2011a). When the cardiovascular system is running in a healthy way, blood is pumped through the body easily, and nutrients are carried to its cells. However, when there are blockages and problems due to high cholesterol, diabetes, high blood pressure, physical inactivity, smoking, and obesity, flow of blood is inhibited, and thus nutrients cannot be delivered to cells (Alzheimer's Association, 2011a; Rocca et al., 2011). As with MCI, not all aging adults with cardiovascular disease will demonstrate dementia symptoms. Rather, it seems that physiological changes that occur may relate to having sensitivity and susceptibility to developing the disease (Alzheimer's Association, 2011a; Erkinjuntti, 2005; Hendrie et al., 2006). Care recipients and caregivers can work together to create healthy lifestyles in

which regular cognitive activity and physical exercise may prevent the formation of dementia.

Head trauma and brain injuries are other risk factors for developing dementia. Head traumas and brain injuries consist of losing consciousness from being hit in the head, or suffering post-traumatic amnesia lasting more than 30 minutes (Alzheimer's Association, 2011a). When individuals experience loss of consciousness or amnesia for more than 24 hours, the injury may be considered severe. Individuals with moderate head injuries are at twice the risk of developing dementia related to AD, and those with severe head injuries are at four times the risk of developing dementia (Alzheimer's Association, 2011a). Depending on lifestyles that individuals live, head injuries might be more or less likely, and thus increase the odds of forming symptoms of dementia. Still, it is a condition that often can be prevented.

Many of the aforementioned risk factors occur as a result of lifestyle choices, and may in some cases be prevented. However, some risk factors are due to genetic and family heritability. In the case of the most common forms of dementia, causes are due to excess and abnormal formations of proteins in and around brain cells, which may be linked with genetic origins. Nonetheless, knowing the risk factors for developing dementia is important to predicting problems for aging adults who have genetic predispositions, preexisting conditions, and/or unhealthy lifestyles. Family caregivers who know the risk factors can help care recipients and themselves in predicting the course of the disease and the treatment that will be needed, which in turn may mitigate the impact that dementia has on the family system.

Dementia Impact

Ultimately, the impact of dementia ends in the passing away of loved ones. In general, degenerative dementias like AD are the fifth leading causes of death for aging adults in the U.S. (Alzheimer's Association, 2011a). In fact, between 2006 and 2008, deaths related to Alzheimer's types of dementia almost doubled, most likely due to the increase in number of aging adults living longer. Sixty percent of individuals age 70 with dementia are expected to die before their 80th birthdays, compared with only 30% of adults age 70 with no dementia symptoms (Alzheimer's Association, 2011a). Additionally, two thirds of individuals with dementia die while living in nursing homes.

Most often, death is due to the complications that dementia frequently causes, including difficulties swallowing and nourishing the body, as well as the development of pneumonia. In light of the loss that occurs because of dementia related problems, dementia seems to be a disease that comes on slowly and causes gradual decline in cognitive and physical health. As stated earlier, dementia patients live an average of four to eight years after they have been diagnosed (Alzheimer's Association, 2011a). During that time, aging adults become dependent on certain types of care and connection with formal and informal caregivers. Thus, the impact of the disease multiplies in that it affects not only the lives of the care recipients, but also of the people who care for them.

Dementia, however, also has a much greater impact on the larger society, especially financially. In the U.S., the incidence of individuals who develop dementia each year is increasing, as is evident in the growing number and variety of formal care services in communities, as well as the information available online. Again, almost \$200

billion is spent on dementia care in the U.S. each year (Alzheimer's Association, 2011a). Additionally, the prevalence of informal care provided by family caregivers is on the rise. As will be discussed in the sections ahead, 80% of dementia care is provided in the home by unpaid informal caregivers – often spouses and adult children of individuals with dementia (Alzheimer's Association, 2011a; Eldercare Partners, 2011; Quinn, Johnson, Andress, & McGinnis, 2003). The trend to provide in-home care for aging adults with dementia has impacted how family members connect with each other and how they live their lives. It continues to influence the family system and usually exacts a heavy price.

Although Medicare and Medicaid pay for some of the costs of care, care recipients and their families pay for a significant portion of care out-of-pocket. The impact of individuals living longer, as well the increased incidence of degenerative diseases like dementia, has shifted how individuals spend money. Both care recipients and their caregivers are paying the price in the form of time and money to alleviate the suffering of aging adults with dementia.

Yet, the impact of dementia is possibly greatest for family caregivers. Caregiving for family members with dementia can be very stressful and may lead to high levels of emotional distress and depression for the unpaid familial caregivers. National Alliance for Caregiving (NAC), Schulz and Cook (2011) reported that those who care for aging adults with dementia are more likely to report increased levels of burden and stress than other types of caregivers, primarily because of care that must be provided to assist with resultant behavior due to cognitive and physical decline. The Alzheimer's Association (2011a) found that 60% of family caregivers rated their stress level as either high or very

high, and Eldercare Partners (2011) found that 40 to 70% of caregivers experience symptoms of depression. The transitions that family caregivers must make when caring for family members with dementia impact their employment, income, financial security, health and daily lives. In addition, stress influences the experience of psychological distress and physical illness (Alzheimer's Association, 2011a). Therefore, beyond understanding the symptoms, causes, and care for dementia, it is important to understand just who is doing the caregiving.

Dementia Caregiving

As cognitive, emotional, and behavioral changes take their course, caregivers are charged with helping dementia care recipients in ways that are vital to their health and wellbeing. Care recipients can be defined as aging adults who have levels of cognitive and physical decline that have caused them to rely on the help of others for their ADLs and IADLs. Care recipients may not be formally diagnosed with forms of dementia, but changes in their personality, behavior, and ability to remember may be initially witnessed by spouses or adult children (HIP & NAC, 2005; U.S. National Library of Medicine, 2012). Additionally, dependent on the conditions of the care recipients, they may require temporary, short-term, or long-term care.

Two types of caregivers become involved in assisting aging adults: formal caregivers and informal caregivers. In the following paragraphs, formal and informal caregiving is defined, the number of tasks and responsibilities are described, and caregiving life-changing affects on caregivers' well being are discussed.

Caregivers Defined

Caregivers can be defined as adult individuals who may or may not be related to the care recipient, but who are charged with the task of securing the physical, mental, and emotional health and well being of aging adults. Adding to the definition of caregiver, those adults who care for aging adults with dementia may be defined as those who are responsible for being aware of cognitive changes in care recipients, and acting accordingly to address and slow the effects of cognitive decline, as well as maintain quality of life. One might intuit that most caregiving for aging adults with dementia takes on similar features. However, dependent on the level of severity of symptoms that care recipients' experience, caregivers may help in different ways, with various services and distinct relationships to care recipients. Still, whether they are providing formal or informal care, caregivers are charged with the duties to keep care recipients safe, nurtured, and experiencing basic wellness for maintaining quality of life.

Formal. Formal caregivers can be defined as direct-care workers and professionals in communities and medical centers that have received some form of training to provide a range of services to care recipients and their families, from phone consultations to residential 24-hour assistance in IADLs and ADLs. Formal care settings include assisted living facilities, nursing, personal care, and adult foster care homes (Alzheimer's Association, 2011a; Quinn et al., 2003). However, these settings also may include agencies and centers that provide consultation to families, help with running errands for care recipients, and/or in-home services (DARTS, 2012; Eldercare Partners, 2012).

Direct-care workers are care providers who perform IADL tasks, like food preparation, laundry services, and maintaining safe and secure environments. They take on the majority of caregiving in formal care settings (Alzheimer's Association, 2011a). Direct-care workers include nurse aides, home health aides, personal-care aides, and home-care aides. On the other hand, professionals who care for aging adults with dementia receive special training to specific nursing and medical services (Alzheimer's Association, 2011a). They include physicians, physician assistants, nurses, social workers, pharmacists, caseworkers, and others. Interestingly, counselors are not mentioned in much of the literature on caregiving. Yet, counselors are noted as "care managers" by Klein (2005) in her description of contracted professionals to advocate, coordinate, and provide needed knowledge and assessment for services for aging adults with dementia and their families. Perhaps, the roles that counselors play in helping caregivers has been downplayed because of the historical focus on primary caregivers and assistance with instrumental caregiving tasks, rather than looking at how counselors can help aging adults with dementia, and their families, find equilibrium and function in harmony.

Although the need for professionals in the field of dementia care is high (Alzheimer's Association, 2011a), the number of professionals working in the field of dementia care is low. This shortage may be due to the lack of adequate monetary compensation, as well as a shortage of professionals being trained in the various facets of dementia care. In fact, less than 10% of aging adults with dementia receive all their care

from paid professionals and trained caregivers (Alzheimer's Association, 2011a). As a result, most caregiving responsibilities have been given to informal caregivers.

Informal. Informal caregivers or family caregivers can be defined as family members and/or close friends who are responsible for the daily needs of other individuals, typically without being paid (Bertrand et al., 2006; HIP & NAC, 2005). “Family caregivers are responsible for the physical, emotional, and often financial support of another person who is unable to care for him/herself due to illness, injury or disability” (HIP & NAC, 2005; p. 10). They consist of spouses, adult children, extended family members, close friends, and even neighbors. However, 83% are related to the care recipient (HIP & NAC, 2005).

In regards to dementia care, living spouses and adult children are often the first to respond to care needs involving challenges due to memory loss and physical difficulties. In these cases, care consists of helping with IADLs (DARTS, 2012; MetLife, 2011). However, caregivers may also assist with ADLs.

Prevalence. Eighty percent of dementia caregiving is done in the home by unpaid informal caregivers (Alzheimer's Association, 2011a; Eldercare Partners, 2011; Quinn et al., 2003). Spouses, adult children, extended family members, friends, and even neighbors come to the aid of aging adults with cognitive decline. In fact, there are 65.7 million family caregivers in the U.S., which represents 29% of the population (AARP & MetLife, 2009). About 10 million of the general population of caregivers consists of adult siblings caring for their aging parents, which represents a three-fold increase in caregiving by family members (MetLife, 2011).

Demographically, caregivers seem to fit a situated role. As might be expected, 83% of all caregivers are women (NAC et al., 2011), while just 60% of dementia caregivers are (Alzheimer's Association, 2011a). The difference may be due to an increased need for both sons and daughters in caring for aging adults who have a number of difficulties caused by their experience of dementia. Racially, there seem to be no real differences in who provides caregiving, with only a slight majority (53%) of caregivers being white (NAC et al., 2011). As for age, about 56% of general care caregivers are ages 55 and older (although, the average age of a family caregiver is 46 years old; HIP & NAC, 2005). However, dementia caregivers' average age is 60.8 years old. The difference is unsurprising considering that the many aging adults with dementia find themselves being cared for by their children. In fact, 52% of care recipients are cared for by someone other than a spouse – primarily adult children (National Alliance for Caregiving, 2011). About 50% of the time, family caregivers live with their dementia care recipient (HIP & NAC, 2005). This is reasonable to expect since most people believe that the care of aging adults should be with their family members, namely their grown children (Kahn & Bank, 1981; Ingersoll-Dayton et al., 2003; Matthews, 1995; Matthews, Adamek, & Dunkle, 1993; Matthews & Rosner, 1988; Rosenthal, Martin-Matthews, & Matthews, 1996).

Beliefs About Caregiving

Generally, caregiving is a concept that is based in context to the perceptions of those involved. Caregiving is defined based on the needs of care recipients and how caregivers perceived those needs (Wallhagen & Kagan, 1993). Unsurprisingly, there are

mixed findings in the literature about where responsibility for eldercare should reside. One study (Seelbach, 1977) found that at least 50% of women and 42% of men believed that care and residence of aging adults should be placed with their children. Yet, Marshall, Rosenthal, and Daciuk (1987) found that most individuals believed that filial care of aging adults should reside with the family in general (81.2%). These differences may arise out of the ideologies of different generations, which may be evidenced by the periods of time that aforementioned research was conducted (Seelbach's research in 1977 and Marshall et al.'s research in 1987). Still, other differences may be due to the demographic make up of different samples of people. In regards to socioeconomic status and race, Seelbach's sample consisted of primarily low-income African American participants, while Marshall et al.'s sample consisted of professional socioeconomic status white participants. Yet, Marshall et al. noted that participants may have responded based on their beliefs about the need to economically support their aging parents, rather than indicating a pattern based on racial background.

Conversely, Dilworth-Anderson, Williams, and Gibson (2002) suggested that ethnic minorities in many ways share the beliefs of the majority population that the caregiving networks should reside in the family of origin. However, generally, minorities defined frame of support network as more extensive than their white counterparts. Where there was a tendency for whites to rely on just family members, ethnic minorities were more likely to include family members, friends, and neighbors in the caregiving support network. Also, they were more likely than whites to seek formal external caregiving support services (e.g., community care services; Dilworth-Anderson et al., 2002). Even

so, white care recipients more often were found to be cared for in formal care settings than were ethnic minorities (Flaskerud, 2009). Although aging adults with dementia who are of African, Hispanic, or Asian American descent were most often cared for at home, this might be related to cultural traditions, lack of resources, and/or lack of knowledge about services (Flaskerud, 2009). Although findings are mixed, it is clear that many people, regardless of generation and race, believe that the family should provide care.

The literature on eldercare, however, has noted differences in caregiving beliefs and behaviors based on two main demographics: age and gender. Matthews (1995) found that younger caregivers expressed less need to provide informal support or initiate formal support and that support was provided more on an as-needed basis. Yet, she found that caregivers who were age 65 and older expressed more agreement about providing support to their aging family members. Sibling caregivers who are older most often provide the most support to aging parents because their parents are of an age where signs of decline are more evident. Also, as spouses pass away, leaving behind the other spouse to care for herself or himself, the need for auxiliary help increases. In many cases, an adult daughter becomes the routine caregiver that provides supplemental support.

Gender very much impacts beliefs about who provides care to aging adults, how it is done, and what is involved (Matthews, 1995; Matthews & Rosner, 1988; Russo, 2010a). In the majority of the literature on eldercare, regardless of race or age, women were more likely to be the primary providers of care than males (Dilworth-Anderson et al., 2002; Matthews, 1995; Matthews & Rosner, 1988; Russo, 2010a). However, Matthews (1995) suggested that the differences in provision of care might not necessarily *only* be gender-

based, but rather may be found in how “care” is defined. She found that female and male siblings provided care in different ways based on a gendered understanding of the social rules of care. In her study, sisters were more likely to take the lead in initiating care and more likely to be involved in assisting with occupational and physical care duties, while brothers were more likely to provide assistance in the form of financial services and legal responsibilities after having been asked by sisters (Matthews, 1995). Still, even with brothers providing some type of support, it was often devalued as unimportant, or not acknowledged. As a result, it might be expected that a majority of sibling caregivers would be sisters because of gender ideals of caregiving. Styles of caregiving also are dependent on a number of factors, including characteristics of siblings, roles, proximity, competing obligations, and family structure (Matthews & Rosner, 1988). For example, brothers may not routinely participate in caregiving as often as sisters, but they may provide it by consistent visits, twice a month.

Beliefs about caregiving certainly impact who and how caregiving is provided to aging adults with dementia. It seems that in the majority of cases the actual responsibility is being given to close family members, primarily adult siblings, to share the tasks of dementia caregiving. Nevertheless, as time goes on and dementia symptoms increase and health declines, a mixture of formal and informal supports might be needed. Dependent on care recipients and their families, the types of caregiving approaches might vary.

Caregiving Approaches

There are a number of ways to approach caregiving. In today’s society, not only are family members caring for aging adults, but providers in community settings also are

helping to provide care. Included are formal supports of elder care and medical services such as home health care, homemaker services, community mental health services, physical therapy, and telephone assurance providers (Wan, 1987). These care providers come from many different care settings and provide support to both care recipients and their families.

Professional caregivers. Many programs exist to support and provide services for aging adults with forms of cognitive decline and their caregivers. Included in these care settings and services are active adult communities, senior apartment communities, independent living communities, assisted living facilities, independent and assisted living facilities, skilled nursing centers and homes, continuing care retirement communities, memory care, elder daycare, and home care (Assisted Living Source, 2012; Spectrum Retirement Communities, 2012). As can be seen, there are many options for aging adults experiencing symptoms that require supplementary care. Additionally, each of the aforementioned formal care settings has its own range of services that it offers to aging adults.

Settings. The many settings created to assist aging adults can be categorized by the level of intensity of caregiving that is provided. Low intensity caregiving settings include active adult communities, senior apartment communities, and independent living facilities. Active adult communities are neighborhoods of single-family homes, townhouses, and condominiums where aging adults (restricted to individuals age 55 and older) can live independently with peers of their own age (Spectrum Retirement Communities, 2012). Although, property maintenance is included with the housing

association fees of active adult communities, no care services are provided to assist with instrumental tasks and activities of daily living. Senior apartment communities are like active adult communities in that individuals age 55 and older rent apartments in a community of like-age peers (Spectrum Retirement Communities, 2012). Again, these settings do not include services for IADLs or ADLs, but typically provide community rooms and social activities for residents. Independent living facilities are low intensity caregiving residences in which staff is available to help with IADLs, such as transportation, meal preparation, and laundry service (Assisted Living Source, 2012; Spectrum Retirement Communities, 2012). Social activities and recreational opportunities also are available. Typically, however, no skilled nursing staff is provided, so residents will not receive ADL care services as a part of living in independent living facilities (Assisted Living, Source, 2012) that may be referred to as retirement homes or retirement communities. As a result, these low intensity caregiving settings attract aging adults who are alert, can manage their own lives, and prefer to live in a community of peers in their age range.

Assisted living facilities provide moderate intensity caregiving. These facilities provide residential care, are state regulated, and not only provide the amenities of independent living facilities but provide a skilled nursing staff to assist with ADLs such as bathing, feeding, and medication maintenance (Assisted Living Source, 2012; Spectrum Retirement Communities, 2012). Oftentimes, there are special floors or wings of these facilities that are dedicated to the care of aging adults with forms of dementia. These facilities also may be called personal care homes, adult family care homes,

residential care facilities, board and care, long-term care facilities, and adult congregate care (Assisted Living Source, 2012). In some cases, independent living and assisted living facilities are combined to offer care recipients the balance of independence and 24-hour care that they need (Spectrum Retirement Communities, 2012). For aging adults and their families who have decided that formal care is needed, these moderate intensity caregiving facilities might meet the care needs of aging adults in the beginning stages of dementia. However, as discussed previously, many people still believe that caregiving should be the responsibility of the family. Researchers also have found that in the beginning stages of aging adults' cognitive decline there may be discord among family members regarding how much care they believe their aging family member requires (Russo, 2010a). As a result, family members may be reluctant to place their aging family member in a moderate level caregiving facility, even when cognitive decline is apparent.

Settings that require high levels of caregiving services include skilled nursing facilities, continuing care retirement communities, and memory care. Skilled nursing facilities, or nursing homes, are facilities where residents can pay for daily or monthly care (Spectrum Retirement Communities, 2012). Individuals in skilled nursing facilities require 24-hour care services for IADLs and ADLs, as well as nursing and medical treatment. Residents in nursing facilities may be aging adults or other adults recovering from an illness or injury (Assisted Living Source, 2012). Therefore, they may temporarily reside in nursing care facilities or maintain a long-term stay depending on their individual conditions. These typically are licensed facilities where Medicare and Medicaid are accepted, that provide care for aging adults with and without dementia (Assisted Living

Source, 2012; Spectrum Retirement Communities, 2012). Continuing care retirement communities also have been created. These are communities that offer a combination of independent living, assisted living, and skilled nursing facilities (Spectrum Retirement Communities, 2012). Although these communities have trained staff members on hand to assist in both IADLs and ADLs, most services are centered toward individuals in independent and assisted living. With limited availability of licensed skilled nursing beds, these facilities often lack the ability to provide intensive care for aging adults with multiple and high levels of caregiving needs, especially those with cognitive decline.

Some aging adults experiencing forms of dementia may require services in memory care settings. Memory care services may be part of in-home, assisted living, and nursing home services in which residents who are suffering from forms of dementia have specific services provided to assist in mediating symptoms of cognitive decline. Memory Care facilities focus on providing safe and secure environments to prevent wandering, and offer brain fitness and memory building activities to moderate the impact of dementia (Assisted Living Source, 2012).

Families who balance both formal and informal care for aging adults may benefit from adult day care, that consists of out-of-the-home caregiving services for aging adults that provide social activities, medical care, and therapeutic opportunities for those who suffer from physical challenges and cognitive decline (Zarit, Stephens, Townsend, & Greene, 1998). The option of adult day care is much like respite care in that it temporarily takes on caregiving duties so that primary caregivers have time to devote to their own wellbeing and life events. In-home elder care is another temporary care-giving service.

In addition, community programs exist that coordinate household services for aging adults and caregiving services and education for family members (DARTS, 2012; Eldercare Partners, 2012). Direct services to aging adults might include in-home assistance with IADLs (DARTS, 2012). On the other hand, direct services to caregivers might include in-home consultations to provide information to caregivers about health concerns, care options, and the balance of caregiving and personal needs (Alzheimer's Association, 2012; DARTS, 2012; Eldercare Partners, 2012). All of these services, however, come at a cost in both time and money. As mentioned above, there are no guarantees on how much Medicaid or Medicare will pay for the care of aging adults with dementia. Consequently, family caregivers must balance the cost of actual in-home or daycare services and the time that they must spend assisting aging adults, which may take away from their own employment, families, and financial freedom.

Various online resources also have been set up for aging adults and their family caregivers. Some focus on helping families locate elder care settings, like Spectrum Retirement Communities (SRC) and Seniors Guide (Seniors Guide, 2012; Spectrum Retirement Communities, 2012). Other online resources help families locate specific rehabilitation, medical, and in-home services for aging adults; examples include Altercare of Ohio (2012) and Grand Assistance (2012). In many cases, information is offered at no cost, although actual assistance is limited to basic guidance in finding possible care facilities.

Finally, some settings and services have been developed specifically for caregivers. Care management is one service that provides geriatric care consultants to

families that offer guidance and assistance in caring for aging family members with dementia (Klein, 2005). These services consist of trained professionals who coordinate and monitor health care services for aging adults on behalf of aging adults' families who cannot participate in daily caregiving tasks. Care managers act as advocates, social workers, and guardians for aging adults with dementia. Additionally, they provide knowledge about the various formal care options, preliminary assessments, meeting daily needs, financial coordination, and family counseling and mediation (Klein, 2005). Hourly rates range from \$85 to \$125 per hour. Many are state-licensed as nurses, social workers, or counselors. The services they provide typically are comprehensive, especially with family counseling and mediation services they offer.

Other online sources offer information and reports on the features, impact, and interventions for illnesses brought on by aging and degenerative diseases. Organizations like the Alzheimer's Association, the HIP Health Plan of New York, and the National Alliance for Caregiving provide a place for caregivers to start navigating, planning, and implementing care plans for their loved ones. *Care for the Family Caregiver: A Place to Start* (HIP & NAC, 2005) is a comprehensive report that includes facts and figures, case studies, and information on what to expect in the caregiving process. In its case studies, the report suggests that, more than just attending to care recipients' IADLs and ADLs, caregivers need to feel a sense of relationship, or connection, and emotional-social support in the caregiving system.

However, settings and their resources such as the aforementioned often focus on the experience of the care recipients and their primary caregivers. They do not explicitly

recommend planning services by examining the caregiving relationship from a family system point of view – where immediate connection and support may or may not be found. Also, although they do suggest getting help from family and friends, the information is tailored for a primary caregiver. Once again, the idea of caregiver is narrowed to a single person, taken out of context of the dynamics of a family system, and perhaps bypassing the resources that already exist in the family. A typical model for these programs is to help family caregivers through pointing them to external resources. However, this model overlooks the presence of multiple caregivers that influences the ability to engage and work harmoniously in a system of care for aging adults – especially those with forms of dementia. Moreover, models that focus on a single caregiver fail to take into account the dynamic social connections and support in individuals' family systems that underlie the caregiving process.

Thus far, the particulars of various care settings and basic services that those residences offer to aging adults and their families have been presented. However, it also is necessary to understand the specifics of what is being offered to care recipients to gain a perspective of what goes into formal caregiving.

Services. Looking across settings, the most frequent services offered include information on specific types of instrumental caregiving support, the course of dementia, expectations of care, and strategies to address caregiving issues (Alzheimer's Association, 2012; DARTS, 2012; Eldercare Partners, 2012). As mentioned above, various settings have been created to accommodate the needs of care recipients, dependent on their levels of independence and impairment. Most of these settings

emphasized the importance of trained staff that fosters safety and security from wandering, accessibility to assistance and daily needs, simplification of daily routines, and monitoring of nutritional needs for aging adults with forms of dementia (Altercare of Ohio, 2012; Grand Assistance, 2012; Seniors Guide, 2012; Spectrum Retirement Communities, 2012). However, in some cases, care settings go as far as to suggest that staff members learn and provide activities that help maintain cognitive health for aging adults with dementia (Altercare of Ohio, 2012; Grand Assistance, 2012; Seniors Guide, 2012). Additionally, other care settings emphasize services that foster participation and enjoyment in activities through “gentle prompting and validation,” and promote continuity and stability through a secure environment and familiar faces (Altercare of Ohio, 2012).

In settings that provide moderate to high intensity of caregiving, attendance to IADLs and ADLs is a priority. These facilities often take care of individuals’ IADL needs, including homemaking tasks, outdoor chores, handyperson duties, grocery shopping, meal preparation, laundry and facility maintenance, running errands, social visitations, and transportation (Assisted Living Source, 2012; DARTS, 2012; Grand Assistance, 2012; Spectrum Retirement Communities, 2012). Other types of instrumental supports can include providing thorough medical exams, medication, and health care, as well as securing a safe and structured environment where clients could experience consistent and stress-free living (Altercare of Ohio, 2012; Grand Assistance, 2012; Seniors Guide, 2012; Spectrum Retirement, 2012). ADL care includes assistance with feeding, bathing, dressing, and other personal care activities.

Additionally, formal care programs for adults with dementia provide information to clients and their families on the symptoms, etiology, and expected course of dementia. For instance, SRC (2012) offers memory care residential living and services. It purports to offer services to aging adults with dementia that connect the individual, family, and care providers. Further, SRC emphasizes care that fosters respect for residents' personalities, values, and preferences. This program also supports practices that allow the active engagement of family members in the entire care process and values understanding the importance of workings of the family as a unified system of care (Spectrum Retirement Communities, 2012). However, SRC does not specify ways that it ensures the engagement of family in the caregiving process, nor what "family" was considered (e.g., primary caregivers, spouses only, adult children, etc.).

Another program, Altercare of Ohio (2012), provides families with information on dementia and resultant behavioral changes that may occur with their aging family member. Additionally, families are educated on ways to cope with the progression of dementia, as well as the treatment strategies and process of care for their aging family member with dementia. The program notes that support groups are available for family members to learn, share, and garner emotional support, external from the family unit. Still, Altercare does not discuss how family support is fostered in each family system.

By contrast, DARTS (2012) elder care of W. St. Paul, Minnesota offers the most comprehensive services with specific programs to assist caregivers of aging adults. It centers its assistance on coordinating services that help both aging adults and their caregiving family members. In particular, it offers coaching and counseling services for

caregivers, respite care, educational programs and support groups, workplace seminars, as well as an online program called CaregiverMN.org. This program targets adult children of aging parents, and the specific successes and challenges that they may face in caregiving situation.

DARTS (2012) offers many innovative and extensive resources for families of aging adults, including coaching and counseling services, respite care, as well as education and support groups. With regard to coaching and counseling for caregivers, DARTS focuses on the needs of spouses and adult children who are caring for aging adults (DARTS, 2012) and aims to foster skills, training, emotional support, balance, and confidence in the caregiving process.

Additionally, DARTS provides respite care to give family caregivers a break to attend to their personal lives, in the event that a back-up family caregiver is not available (DARTS, 2012). With this assistance, volunteers stay with aging adults, while caregivers take breaks. Respite care is offered for up to four hours at a time.

Furthermore, DARTS offers, education and support groups to assist family caregivers in making housing decisions, legal and financial choices, dementia and memory loss knowledge and community resource awareness (DARTS, 2012). Caregivers receive information and guidance about in-home care, independent senior housing, assisted living, and nursing homes. Additionally, they are provided with information about handling power of attorney, specialized insurance, and financial needs for their aging family members. Strategies for caregiving are discussed, including maintaining dignity and connectedness in caregiving, as well as the importance of having critical

conversations with all family members about cooperative care, balancing work, and making decisions about elder care (DARTS, 2012). In particular, the program emphasizes the importance of family dynamics and how things like inheriting property and conflicting personalities often present difficulties in caring for aging family members. Family caregivers also have access to more information from discussion forums related to distance caregiving, Lesbian/Gay/Bisexual/Transgender caregiving, resilient caregiver setting of limits, and sharing of caregiver thoughts (DARTS, 2012).

In the aforementioned aspects of DARTS, it can be seen how the program goes more in-depth about the particular concerns that caregivers, specifically adult children, are going through. To help caregivers, it offers support groups for caregivers from different families to discuss issues and obtain knowledge from professionals. However, although important filial care issues related to legal, financial, and personal caregiving come up, the actual importance of connecting these sibling caregivers is not indicated as part of the services provided.

A partner site, CaregiverMN.org, provides detailed information about the concerns that may arise for caregiving adult children (DARTS, 2012). Examples of topics discussed include accepting parents' aging, self-ratings of caregiving typologies, questions to ask self before caregiving, information about deciding to care for parents, getting help from other family members, sharing tasks and supporting fellow caregivers, dealing with feelings and past conflicts, and organizing care plans. Surprisingly, it is the only elder care organization that specifically addresses family dynamics that may foster or impede caregiving for aging parents. In fact, this program builds off of some of the

most important research to date on sibling dynamics in the caregiving process, particularly drawing on Sarah Matthews and Tena Rosner's (1988) typology of caregiving styles. This is important because it is one of the only programs to suggest the importance of looking at the roles that each of the caregiving adult siblings take on as part of the family system of care, rather than looking at it from a single caregiver point of view.

A limitation of this approach is that the research to support it is almost 25 years old. There may be differences in modern day sibling relationships that change sibling involvement and influence in the caregiving system for aging parents, especially those with dementia. There have been more recent studies that also suggest the importance of examining the dynamics of caregiving from the sibling unit point of view (Ingersoll-Dayton et al., 2003). Still, many of these studies are based on information from only one or two siblings in the family system and do not consider the dynamics of sibling connections, filial social support, and family system issues.

In conclusion, a great variety of settings and services exist in the formal care arena for aging adults, especially those adults with forms of dementia. Many of them focus on the concrete tasks and basic needs of care recipients. Additionally, of the few that discuss the importance of including the extended family in the care, many seem to focus on the "primary caregiver" as opposed to the system of family caregivers. One program, DARTS, offers comprehensive services based on the progressive research by Matthews and Rosner (1988) that included all potential caregivers in the system as part of the caregiving process and discussion and planning of care. Still, that program bases

much of its information on research that is more than twenty years old. Therefore, it is important to understand the experience of caregivers of aging adults with forms of dementia, from a current point of view.

Family caregivers. Another aspect of caregiving is informal care. Informal care consists of services provided by close family members and friends of aging adults with dementia. Typically, spouses or adult children provide care to aging parents with dementia (Cantor, 1992). Still, with the increase in adults living longer, the potential for adult children (adult siblings) to be caregivers is increasing. In a report by MetLife (2011), daughters and sons of aging parents with dementia generally provided equal amounts of caregiving to their aging parents, but more daughters provided personal care assistance, while more sons provided financial assistance. This is not surprising considering the stereotypical gender roles in caregiving that have been discussed previously

Like formal care, informal caregiving included assisting in IADLs and ADLs (Alzheimer's Association, 2011a; HIP & NAC, 2005; Russo, 2010a). Oftentimes, family members balanced caregiving tasks with the personal duties of their lives, including employment, having their own families, and personal free time (Matthews & Rosner, 1988; HIP & NAC, 2005). Moreover, even when aging adults went into formal residential care type settings, family members continued to assist with financial and legal concerns, oversaw arrangements for medical care, provided emotional and social support, and sometimes continued helping with ADLs (Alzheimer's Association, 2011a). This finding is not surprising in light of the filial expectations of care that are passed on, that

care should be placed in the hands of adult children caring for aging parents with dementia. Thus, adult children may feel the need to stay personally involved in the care of their parents, regardless of where their aging parents are residing and the severity of symptoms they might experience. In fact, researchers have found that as cognitive and physical health declines for aging parents, active participation in caregiving increases and adult children feel more need to be involved (MetLife, 2011; Russo, 2010a).

Other ways that family caregivers provided support to their aging family members were in advocacy. The Alzheimer's Association (2011a) found that about 60% of caregivers performed some kinds of advocacy tasks for aging adults with dementia, usually through contacting government agencies and care providers. Connecting with national organizations such as the Alzheimer's Association, National Alliance on Caregiving, MetLife Mature Market Institute, and the National Family Caregiver Support Program were ways in which advocacy for aging adults, and the families who care for them, had the benefit of resulting in more information about the caregiving process and impact (Alzheimer's Association, 2011a; MetLife, 2011; HIP & NAC, 2005). In fact, the HIP Health Plan of New York and the National Alliance for Caregiving (HIP & NAC, 2005) released a report that listed a number of caregiving resources for primary caregivers and care recipients, as well as ways to connect with organizations that advocate for care recipients and caregivers. Resources included information on tasks of caregiving, housing for care recipients, aging resources, mental health services, and general information on AD.

It is truly amazing the number of ways that informal family caregivers support their aging family members, especially those with dementia. Not only are they learning new skill sets to accommodate levels of needs that care recipients have, but they also are rearranging their schedules, making sacrifices in their lives, and advocating for the aging family members that they love. Many hours are being spent on caregiving tasks.

It is estimated that family caregivers put in \$17 billion worth of hours of unpaid dementia care per year, which is about 21.9 hours per week (Alzheimer's Association, 2011a). If caregivers live with the aging adult with dementia, the amount of unpaid time increases. Eldercare Partners (2011) found that general caregivers for aging adults spend an average total 4.6 years caring for aging adults. For dementia caregivers, the National Alliance for Caregivers (2011) found that they spend an average 7.9 hours daily on caregiving duties, more than a full-time job's worth of time, including time spent on weekends. Many caregivers are still employed or trying to keep their jobs, so adding another full-time responsibility of caregiving may create significant burdens for caregivers and create stress from competing obligations. Moreover, caregivers may feel a lack of social support in navigating the emotional, mental, and physical changes that they must endure. As a result, burden, competing obligations, and lack of social support can impact the integrity of caregiver wellbeing.

Caregiver Wellbeing

As mentioned above, a majority of aging adults believed their children should assist in their eldercare. Actually, Brody (2001) reported that some states had laws that a “legally responsible relative” care for aging adults in their old age – namely adult children. As mentioned previously, the National Alliance for Caregiving (2012) estimated 65.7 million adults in the U.S. were caring for an aging family member or someone close to them – nearly 10 million are adult children. Moreover, Russo (2010b) noted that 43% of adult caregivers said, “they did not feel they had a choice in the role” (p. 44). The occurrence of adult siblings taking on these responsibilities is evidence of the powerful familial and social structures that influence individuals’ behaviors. But as noted by Russo, it does not mean that adult siblings approach parental caregiving without conflict.

In studying the literature on dementia care, three main issues that impact caregiver wellbeing emerge: experiences of stress in caring for aging adults with dementia; competing obligations in multiple roles; and, lack of perceived social supports in the caregiving process. Researchers found that those who care for aging adults with dementia were more likely to report higher stress and burden than other caregivers because of the challenges in providing care for cognitive decline and physical disabilities (Alzheimer’s Association, 2011b; Bertrand et al., 2006). Furthermore, they found that dementia caregivers experienced more emotional strain, mental and physical problems than caregivers caring for aging adults without dementia (Bertrand et al., 2006).

The burden that caregivers experience may arise from the consequential behavior changes that care recipients demonstrate when they begin to experience cognitive decline.

In fact, researchers have found that dementia symptoms and resulting behavior changes are related to caregivers' perceptions of personal stress (Sink, Covinsky, Newcomer, & Yaffe, 2004). These behavior changes include combativeness, wandering, constant talkativeness, hallucinations, unreasonable anger, sleeplessness, and waking caregivers. Sink et al. (2004) found that most aging adults with dementia in their sample exhibited at least one dementia related behavior change. Theoretically, the more dementia related behavior changes, the more stress for caregivers. However, the full picture of what is occurring in the caregiving system was not represented in the aforementioned study. Like most studies that examine dementia caregiving, information was collected from designated primary caregivers, rather than examining all members of the family system of care. Again, the context of caregiving is left out of the equation in understanding the experience of care recipients and their caregivers. As will be seen, caregivers have multiple roles that they participate in addition to their duties as caregiver. Additionally, caregivers' self-efficacy and harmony in the caregiving process really depends on their perceptions of connection and social support. Thus, it is crucial to understand the rising stress, the competing obligations, and the lack of felt connection and support that contribute to the experience of burden and the impact on caregivers' wellbeing.

Burden. Caregivers' perceived burden seems to be related to a confluence of factors, including caregiver appraisal of their stress experience, depression, perceptions of control, and physical health. To begin with, caregivers often experience a tremendous amount of stress. Researchers have found that family members caring for individuals with cognitive problems may be more stressed than the care recipients themselves (Gan

& Schuller, 2002). Sixty percent of family caregivers rated stress of caregiving for aging adults with dementia as either high or very high (Alzheimer's Association, 2011a), as compared to 31% of nondementia caregivers who rated stress as high to very high (Eldercare Partners, 2011). Many times, stress also was related to money or relationship problems. The Alzheimer's Association (2011a) found that 56% of individuals reported that a good amount to a great deal of stress was due to financial issues of caregiving, and 53% reported that it was due to family relationships. Financial worries are not surprising when considering the high cost of caregiving for family caregivers. Possibly the growth of formal care settings and services resulted from the need to help family caregivers with the many costs that go into caregiving. However, even with financial support from Medicaid and Medicare, family caregivers are still left with financial burdens and stresses.

On the other hand, stress from family relationships, while not entirely surprising, has been something that seems not to have received sufficient attention. As will be discussed, spouses and adult children of caregivers seem to meet their caregiving duties with a mindset that their family members, and other individuals in the caregiving system, are as they were in their family of origin. Frequently, however, significant changes have occurred, roles have reversed or been modified, ways of relating have been reorganized, dynamics have changed, and duties have transformed. Yet, family members may miss opportunities to discuss new ways of coming together in the care process. Many times this conversation gets lost in efforts to reach for some external remedy for resolving caregiver burden.

As a result, many family caregivers rely on external caregiving resources with uncertain results. Researchers found that dementia caregivers experienced stress of caregiving even after putting their aging family members with dementia into residential care (Alzheimer's Association, 2011a; Zarit, Stephens, Townsend, & Greene, 1998). For example, Zarit et al. (1998) found that formal daycare for aging adults with dementia helped relieve caregiver stress about caregiving tasks. However, caregivers continued to experience role captivity and feelings of being forced, trapped, and burdened in the role of dementia caregiver. In other words, they continued to feel the burden and stress, even with assistance from formal care. As mentioned above, about half of people believe that family relationships contribute to stress. Therefore, when formal care gets involved, it seems to only relieve the instrumental tasks of caregivers; emotional and social support in the family seem to be set aside, so focus can be placed on the care recipients. Although there were limitations to Zarit et al.'s (1998) study, including the homogeneous treatment group, even with formal care assistance, caregivers still report stress and burden in the role of dementia caregiver.

Other researchers have found that hourly commitments to and levels of intensity of caregiving impacted burden. Researchers discovered that dementia caregivers experienced greater hours and higher intensity of caregiving, increased care recipient behavior problems, higher stress, and more role captivity, compared with nondementia caregivers (Pinquart & Sorenson, 2003). Additionally, increased care recipient behavior problems (most likely resulting from declining physical and cognitive health) were positively correlated with increased caregiver reports of burden and depression. However,

care recipient behavior problems had a greater influence on caregiver burden than on caregivers' experience of stress and depression (Pinquart & Sorenson, 2003). Thus, the more outwardly displays of "acting out," the more caregivers felt burdened and captive in their caregiving roles. Yet, role captivity did not relate to perceived stress in dementia caregivers, possibly indicating compliance with and toleration of the role of caregiver. Still, role intensity (the number of hours and types of care, including ADLs and IADLs) was found to increase perceived stress. Interestingly, changes in care recipient behavior increased sense of burden and perceived role captivity for caregivers, but no more stress than nondementia caregivers. However, caregivers who were engaging in several hours of caregiving, with several duties, were found to be more stressed (Pinquart & Sorenson, 2003).

Pinquart and Sorenson (2003) recommended conducting more research on the experience of role captivity, because it is not understood how perceived experiences of burden and role captivity impact caregiving relationships. Curiously, although their research looked at care recipient-caregiver dyads, there was not much discussion of relationships between individuals in dyads. More importantly, the research did not mention any consideration or limitation of the study in leaving out influences of family systems of caregiving and all parties involved (or not involved). Again, in order to understand dynamics that contribute to experiences of stress in dementia caregiving it is crucial to understand how all members of the system of care influence psychological and physical experiences of caregivers.

With increased levels of stress, it is not surprising that some caregivers encounter symptoms of depression. Eldercare Partners (2011) reported that, in general, between 40 and 70% of caregivers experienced clinically significant symptoms of depression. Considering the vast amount of changes that occur for family caregivers, including compromising of routines and free time, it is easy to see how caregivers can begin to feel a sense of emptiness, sadness, loss of pleasure, insomnia, fatigue, worthlessness, scatteredness, and hopelessness, all features of clinical depression (American Psychiatric Association, 2000). In contrast, the Alzheimer's Association (2011a) found that 33% of family caregivers of aging adults with dementia reported symptoms of depression. At first glance, this may seem surprising considering the amount and intensity of demands placed on dementia caregivers. However, lower levels of depression may be related to differences in the amount of formal care involved. As mentioned previously, feelings of stress by caregivers related more to the amount and intensity of tasks, so perhaps dementia caregivers in the Alzheimer's Association (2011a) study had more formal assistance on caregiving tasks of high intensity, resulting in fewer symptoms of depression. Additionally, the samples of caregivers from Eldercare Partners (2011) covered a broader category of caregivers (not just dementia caregivers), so characteristics of the individuals who represent the larger range (70%) are not apparent. Clearly, there are discrepancies in understanding the emotional experience of caregivers that may relate to the relationships in the caregiving system. Perhaps, more investigation of the members in the family system of care could shed more light on caregivers' experience of depression.

Psychological occurrences of stress and depression also may be explained by caregivers' perceived control in caring for aging adults with dementia. Possibly, exacerbating responsibilities is that dementia caregivers care for aging adults with diseases that are unalterable and progressive, thus, uncontrollable. Wallhagen and Kagan (1993) found that caregivers experienced a sense of control in varying ways, including active involvement, receiving contextual feedback, balancing self limits and other limits, and keeping the caregiving situation within reasonable limits. Regardless of how it was experienced, Wallhagen and Kagan found that all caregivers in their study expressed some way that they needed to maintain their sense of control in order to continue in the caregiving role. Yet, these researchers noted that achieving a sense of control in caregiving processes was a persistent challenge. They recommended that caregivers know their resources, pointing out how it is especially important in caregiving situations to predict timing and needs for particular resources for care recipients. Still, they leave out the role of social support in balancing constant challenges to maintaining a sense of control. Additionally, individuals' beliefs about control are situated in the context of cultural, historical and gendered ways of their societies. Therefore, perceptions of control may be based on more comprehensive ways of viewing care recipients, caregivers, and caregiving processes.

Furthermore, Wallhagen and Kagan's (1993) study looked at perceptions of individuals who labeled themselves as primary caregivers. Yet, looking at primary caregivers' perspectives offers only one point of view of caregiving processes.

Conceptions of control in caregiving systems are greatly distorted when looking at only

one individual experience out of context of the family system. Thus, it is crucial that caregiver burden is examined from a family systems framework to understand the nature of caregivers' stress, emotional responses, and sense of control.

Problems related to physical health of dementia caregivers can be another source of tremendous stress. Forty-three percent of individuals reported that caregiving for their family members with dementia had a severe negative impact on their physical and emotional wellbeing (Alzheimer's Association, 2011a; MetLife, 2011), while 17% of non-dementia caregivers reported that their overall health had declined as a result of caregiving (Eldercare Partners, 2011). More specifically, the Alzheimer's Association (2011a) found that 66% of family caregivers were overweight or obese, and that family dementia caregivers were more likely to report negative physiological changes than caregivers who were not caring for individuals with dementia. Physiological changes included high levels of stress hormones, hypertension, and cardiovascular conditions (Alzheimer's Association, 2011a). In addition, emergency room visits were twice as high for dementia caregivers and physician visits were three times as high compared with non-dementia caregivers (Alzheimer's Association, 2011b). Moreover, mortality rates for caregivers, age 66 to 96, was sixty-three percent higher than for those who were not in the caregiving role (Eldercare Partners, 2011). Clearly, burden of caregiving can take a significant toll on caregivers' health.

Moreover, in a recent study, researchers found that over an 18-month period, self-reported health of caregivers significantly declined, from an average rating of 3.02 to 2.91 (NAC et al., 2011). Furthermore, the use of medical services, primary care services,

and mental health services increased for caregivers of aging adults with dementia. It was estimated that caregivers of aging adults with forms of dementia spent an additional \$4,766 per year on their own healthcare as opposed to nondementia caregivers. More specifically, as aging family members' dementia increased, caregivers' self-rated health scores decreased steadily and significantly over 18 months (Alzheimer's Association, 2011b).

Thus, burden for dementia caregivers seems to be experienced in various ways. Caregivers feel stressed related to finances and relationship problems, psychological symptoms of depression and perceived loss of control, and physical decline. However, discrepancies in caregivers' perceptions of stress, role captivity, depression, and control make the root of that burden unclear, and consequently complicate the task of finding solutions that work for family caregivers of aging adults with dementia. Surely, caregiver wellbeing is related to a system of various factors and obligations.

Competing obligations. Caregivers of aging adults with dementia must balance tasks and their own wellbeing with other commitments in their lives. In caregiving processes, dementia caregivers are responsible for out-of-pocket costs of dementia care, as well as household chores, errands, and necessary paperwork to keep care recipients safe, secure, and their basic needs met. Additionally, caregivers experience reduced time for personal activities and leisure time, as well as reduced emotional and financial resources available for their own children and grandchildren (MetLife, 2011). Moreover, many reported experiencing a loss of time with other friends and extended family members.

This group of caregivers who care for both their own children and their aging parents is referred to as the “sandwich generation” (MetLife, 2011; Russo, 2010a). Most often, offspring of the Baby Boomer generation are considered the sandwich generation because as these adult children of Baby Boomers try to balance life caring for their own children, their parents are living longer and needing their daughters’ and sons’ assistance in day-to-day living tasks. They are “sandwiched” between caring for two different generations (MetLife, 2011).

Other researchers, however, have found that only 7% reported falling in the “sandwich” role of caregiver (Rosenthal et al., 1996). Rosenthal et al. (1996) found low percentages of daughters who were caring for a child in the home, employed, and caring for their aging parents, ranging from zero percent to a high of seven percent (depending on age group). Also, low proportions of sons were in the same position of multiple roles indicative of a sandwich generation, with a range from three percent to eight percent, dependent on sons’ age ranges. Furthermore, seven percent of daughters provided personal care monthly and 13% yearly to aging parents, while only one percent of sons provided monthly personal care, and three percent provided yearly personal care (Rosenthal et al., 1996).

Additionally, Rosenthal et al. (1996) found that small proportions of adult children actually provided financial assistance (1 – 5%), house maintenance (1 – 12%) and yard work (1 – 10%). The data from this study were collected some twenty years back, so may not be characteristic of what is actually going on now. However, it is interesting that the idea of the sandwich generation is often touted in the literature; even

when more than half of caregivers are age 55 or older and their kids are out-of-the-home (HIP & NAC, 2005). Perhaps, there are more than just competing obligations of caring for individuals' nuclear families and aging parents. Possibly, there are issues in the family systems of these primary caregivers that actually are contributing to the burden that adult siblings feel when caring for their aging parents. Researchers suggest that to understand dynamics and roles that exist in family systems of those caring for aging parents, that research on families must be done (Rosenthal et al., 1996).

Also competing with caregivers' time is their own employment. Half of caregivers of aging family members with dementia reported being employed either part-time or full-time (Alzheimer's Association, 2011a). Eldercare Partners (2011) reported that 73% of caregivers were employed at some point during their caregiving. Other researchers found that 60% of caregivers reported changes to their job situation as a result of taking on caregiving tasks (HIP & NAC, 2005).

Most caregivers reported that they had to take flextime to care for their aging family members with dementia (Alzheimer's Association, 2011a). Eldercare Partners (2011) reported that about two-thirds of caregivers who are employed in some capacity said that they had to go in late to work or take time off. Twenty percent of caregivers reported having to take a leave of absence due to caregiving responsibilities (Alzheimer's Association, 2011a). Other studies have found that more than 30% of caregivers leave their jobs or greatly reduce their working hours to care for aging family members; women are more likely than men to leave their jobs once they begin to care for an aging parent (MetLife, 2011). Additionally, both sons and daughters reported missed opportunities for

promotions and missed work-related travel, relocation, and continuing education because of caregiving.

Taking into consideration the number of new tasks that caregivers must learn in the caregiving roles, and then coupling that with burden and competing obligations of work and family, caregivers seem to burn the candle at both ends. Numerous formal supports are available to family caregivers in informal care processes of caring for aging adults with dementia. However, caregivers continue to feel burden, stress, and difficulties of balancing it all – they continue to experience emotional and mental strain, oftentimes feeling isolated from any form of social support.

Absence of social support. What is probably least understood about experiences of family dementia caregivers is the involvement of socially supportive beings in their lives. Dilworth-Anderson et al. (2002) conducted a review of the literature on caregiving for aging adults and found some interesting patterns of social support in experiences of caregivers. They looked at approximately 60 articles on caregivers from 1980 - 2000. From their analysis they found four main themes: 1) occurrence of negative impact on mental and physical health, 2) presence of cultural effects, 2) reports of coping issues, and 4) deficits in social support. In particular, caregivers' perceived social support from family members and friends seemed crucial to their experience of mental and physical health, positive cultural experiences and coping. Specifically, Dilworth-Anderson et al. found that despite cultural differences in the make up of caregivers' social support systems, caregivers relied far more on informal family support rather than formal healthcare systems in dealing with caregiving issues. Most often, however, caregivers

expressed low satisfaction with their social support quality and decreased amounts of social activity because of their roles as caregivers. Additionally, the more emotional support that caregivers felt in their social support networks, the more positive outcomes they experienced. This is an especially interesting finding because it challenges present reliance on formal care services and instrumental support in assisting family caregivers to aging adults with dementia. Thus, it may not be the actual formal care and instrumental tasks that need to be explored in understanding caregivers' satisfaction and coping. Investigating caregivers' social support from the emotional and mental points of view might introduce a new perspective on caregivers' needs and ways of coping with caregiving situations. In addition, exploring caregivers' experiences from a systems point of view may shed light on dynamics going on in families and support networks that influence care recipients and their caregivers.

Other researchers have further explored support that caregivers experience when caring for aging adults with cognitive impairment. Adams (2006) conducted an exploratory phenomenological study on caregivers for aging adults with MCI and/or the beginning stages of AD and other dementias. She examined personal experiences and stories of 20 spousal caregivers. She found that even with all the life adjustments, added roles, and increased stress, caregivers were reluctant and hesitant to ask for help or accept solicited assistance from family and friends or from formal care services. Adams found that participants expressed fear of being a burden on other potential caregivers, receiving criticism or unhelpful advice, and concern that their decisions would not be understood. So possibly, it is not just the absence of social support, but the actual perceptions of

caregivers that contribute to the experience of stress and strain due to lack of social support. Moreover, Adams (2006) found that caregivers were reluctant to take action to help in more involved ways because of strong desire to maintain things as they always had been. In family systems theory, this type of behavior would be explained by the family unit's need to maintain the status quo in balancing transition (Hecker, Mims, & Boughner, 2003). Moreover, it is possible that these primary caregivers' reports, which most researchers rely upon heavily, are particularly biased to maintaining negative feedback loops (Hecker et al., 2003) that started in their families of origin years and years before caring for aging spouses or parents.

In conclusion, struggles of family caregivers seem to be affected by the presence or absence of social support. Caregivers often feel a lack of social support in caregiving processes that contributes to their mental and physical health, as well as their ability to cope with the numerous changes that they encounter. Still, some caregivers are reluctant to seek social support due to not wanting to be a burden, receiving criticism, not being understood, or just wanting things to stay the way they always have been. In this way, much focus is placed on what caregivers are doing for care recipients. However, who cares for the caregiver?

Caring for the Caregiver

With responsibilities of caregiving, especially for dementia, come stresses, burdens, and requirements to find ways to assimilate. Much attention has been placed on care and support that caregivers give to care recipients. Yet, limited information exists on how caregivers care for themselves. Of the information out there, foci of interventions are

primarily on improving family caregiver knowledge, skills and well being, as well as decreasing caregiver burden and becoming aware of changes to be made with nursing home placement of aging family members with dementia (Alzheimer's Association, 2011a; DARTS, 2012). Much guidance comes in the form of psycho-education. Frequently, psycho-education is dispersed through structured programs that inform families about the nature and course of dementia, resources and services to aid in the care of those with dementia (Alzheimer's Association, 2011a; DARTS, 2012).

Additionally, information is exchanged through direct support resources. Specifically, some programs offer group therapy for caregivers as an outlet for members to share their feelings and experiences of caregiving. In these groups, members share their experiences and offer advice and support to each other (Alzheimer's Association, 2011a; DARTS, 2012). Group members typically are those caregivers labeled as "primary caregiver" coming together to share their insights, and not necessarily family members gathering to find solutions. As a result, these groups may offer a place to vent about problems, but may not be the best place to find solutions to family concerns.

Other programs offer psychotherapy in the form of individual therapy between the primary caregiver and trained therapy professional. Usually, emphasis is on teaching cognitive behavioral skills to manage maladaptive thoughts, fostering problem solving, bolstering time management, managing emotions, and engaging in positive experiences (Alzheimer's Association, 2011a). From a counseling point of view, the aforementioned therapy strategies can be very beneficial to some individuals. When the root of the

problem is in the family unit, however, individual therapy may miss the problematic patterns that must be solved within context of family systems.

In addition, some programs recommend multicomponent plans for caregiver self-care. Two organizations with the most comprehensive information for caregivers are the Alzheimer's Association and DARTS. Both organizations suggest the inclusion of multiple interventions to help family dementia caregivers (Alzheimer's Association, 2011a; DARTS, 2012). Their recommendations include combinations of formal and informal caregiving to aging adults with dementia, as well as combinations of individual and family therapy to encourage solution finding in caregiving systems. Yet, no clear model has been created that incorporates the multitude of issues that families go through in caregiving processes.

Many existing resources for caregivers to care for themselves are offered online, including some that have already been discussed, including the Alzheimer's Association, the National Alliance for Caregivers, DARTS, Eldercare Partners, and more. Other online resources provide a place for caregivers to blog and discuss issues. For instance, www.mycarejourney.com provides practical information, personal stories, and suggestions about caregiving for aging parents. Caregivers can share with other caregivers across the country about what they are going through. Still, although these resources may be useful in resolving instrumental tasks, it may not address the social and emotional concerns that caregivers face in caring for aging adults with dementia.

Some literature on caregivers' wellness emphasizes caregivers taking individual responsibility over their health (MetLife, 2011). Dementia caregivers need to maintain

their health while trying to care for their aging parents. In particular, caregivers may benefit by making sure they get regular medical check ups and engagement in prevention activities to support balanced and healthy states of being (MetLife, 2011). Thus, by caring for themselves, caregivers can more effectively care for care recipients. It seems like an easy enough venture, yet with the complex system of events occurring in caring for aging adults with dementia, it may be easier said than when the fragility of aging family members' health is on the line.

Other organizations support the need to consider the wider macrosystem of caregiving as an arena to help caregivers. In a report by MetLife (2011), a call is made for employers to accommodate families who are supporting their aging parents. It declares the need for companies and organizations to provide information on planning for retirement, flextime and medical leave, connection with eldercare resources, and access to stress-management programs. This call is somewhat revolutionary in that it supports a community-system point of view of helping families deal with family system concerns of caring for aging adults with dementia.

Nevertheless, programs that advocate care for the caregiver neither list the importance of family therapy as an intervention, nor do they emphasize a systems approach to addressing caregiver concerns. Certainly, there are researchers that advocate for connecting with family caregivers on some levels. For instance, Flaskerud (2009) highlighted how “mental health nurses” need to foster development of “trust, communication, and collaboration with caregivers and designated family spokespersons” (p. 523). Additionally, she goes on to recommend that mental health nurses must

coordinate care that provides information on availability of “long term care, respite care, support groups, and individual and family counseling” (Flaskerud, 2009; p. 523). Yet, there are still very limited resources of family counseling for those caring for aging adults, and there are no models of addressing expansive issues that come up for family caregivers – namely, caregiving siblings.

Caregiving Siblings

Early on in the aging process, spouses may provide the majority of care to their aging partners. Ultimately, however, care must be placed in hands of someone else when aging parents are unable to care for themselves sufficiently. Often, responsibility is given to adult children of aging adults. Accordingly, understanding ways siblings generally connect, as well as how they work together on caregiving tasks, is necessary. Indeed, adult children frequently choose to or have to take on caregiving responsibilities for aging parents (Cantor, 1992). By understanding the general connections of siblings, insight may be gained about the importance of siblings working together in the task of caring for aging parents with dementia.

Sibling Connections

Sibling relationships represent unique bonds between individuals. They may be the most influential of attachments because they are the only ones that are with us continually from early on in our childhood development through our adulthood (Kluger, Carsen, Cole, & Steptoe, 2006). As a result of the longevity that can be sustained in sibling relationships, the power of creating a solid partnership can emerge. The bond that can be realized among siblings serves as a basis of nurturance, guidance, and social

connection for people to grow into well-adjusted and healthy human beings (Lewis, 2005; Namayslowska & Siewierska, 2010).

Sibling relationships are the most frequent and wide reaching type of bonds (Cicirelli, 1995; Sanders, 2004). It is estimated that at least 80 percent of people have siblings (Sanders, 2004). Thus, the probability that end-of-life care for aging parents will be shared among siblings, regardless of type of involvement, is great. Furthermore, sibling relationships represent an “archetypal image” passed on through our cultural stories, values, and mores of childhood (Sanders, 2004). The notion of siblings is something that has historically been passed on in every culture, through legend, folk stories, art, music, and the like. Accordingly, it is not surprising that embedded expectations of how and by whom aging parents will be cared for exist and are passed on through generations.

Another point that differentiates sibling connections from others is their structure of communication. Researchers point to differences in relationships between parents and their offspring, as well as different relationships between siblings. In parent-child relationships, there is a hierarchical standard of communication where children follow rules and cues of their parents (Lewis, 2005; Sanders, 2004). By contrast, sibling relationships take on a more peer-oriented and equal ground of communication. Siblings take responsibility for developing and maintaining jointly shared communication in a more egalitarian way. Together, they learn to share, cooperate, and protect one another.

Thus, generally speaking, sibling relationships represent unique connections that have the potential to support brothers and sisters through their lives. In fact, most older

adults keep in contact with their siblings until late in life (Cicirelli, 1995). Usually, there is a decrease in regular contact as siblings move from childhood companions to independent adults, by American standards. Even though there may be reduced contact, however, older siblings have reported increased feelings of closeness with their siblings later in life. Additionally, researchers have found that the companionship and support that siblings provide one another serves as a critical function to individual development over the lifespan (Cicirelli, 1995). As a result, siblings, who share the responsibilities of caring for aging parents, stand to benefit from supportive resources found within their sibling relationships.

Nevertheless, there are a number of issues that come together to impact working relationships of sibling caregivers. Common themes in the literature relate to four main issues that siblings need to address when taking on responsibilities of caring for their parents: 1) family expectations about filial care, 2) roles played in the family of origin, 3) sibling caregiver factors, and 4) caregiving typology.

Family Expectations

Family expectations about filial care seem to relate to perceptions that siblings have of their parents' needs for care, as well as gender expectations (Matthews, 1995; Matthews & Rosner, 1988; Russo, 2010a). Adult children may involve themselves based on their personal perceptions of their parents' care needs. Matthews (1995) found that although siblings often agree on facts of their parents' health and daily living concerns, interpretation of facts created differences (e.g., advanced age of parents could be agreed upon, but degree of assistance that parents needed, and who were the responsible parties,

was up for debate). Matthews found three interconnected factors that influenced family expectations of filial care for parents: 1) cultural assumptions adopted by the family; 2) ideals that sisters were the ones in charge; and, 3) consideration of contributions by brothers as unimportant or of minimal use. She discovered that families passed down cultural definitions of who were the responsible parties associated with caretaking and family work duties, with those usually being the women in the family (Matthews, 1995). Additionally, in many cases it was adult siblings' parents that called on their daughters to assist them and who thus supported the cultural gender-appropriate behavior that women in families take care of families.

Consequently, aging parents' adult children are influenced by gendered ideals that their parents were raised on (perhaps based on generational differences), regardless if they fit the contemporary standards or roles that adult sibling caretakers' may live by in their personal lives. Russo (2010a) suggested that certain gender biases might be particularly intense in the generation of individuals who raised their kids in the 1950s, also referred to as the "silent generation." An example might be for some aging adults from this generation to value visits of their sons more and see their sons' actions as more notable than their daughters. Although researchers have found no clear cohort effects for generations connected with events of certain time periods, it was in individuals' personal meanings and stories about their generation that cohort effects were visible (Westerhof, 2010). These kinds of generational ideologies seem to be evident in roles that sibling caregivers play and styles of care that they provide.

Yet, families have historically relied on women to do caretaking. Over time, this behavior has come to be the rule, with many families expecting women to know more about caregiving than men, and (making that assumption) implying that if one group knows more about something, then that group should be the one to take on responsibility. This leads to Matthews' (1995) second interconnected factor of sister being in charge. Ideas about what it means to be female and what it means to be male are not just historical artifacts passed down, but they are presently lived and believed by the many members of society. Matthews (1995) noted that "because women are viewed as the appropriate family member to be nurturers and involved in domestic labor, the sister in each family was likely to view herself, to be viewed by her brother, and...in most cases to be viewed by her parents, as being "in charge" of parent-care arrangements" (p. S315). And in 37 of the 40 cases that Matthews examined, sisters did take initiative and leadership when it came to caring for their aging parents (Matthews, 1995). Although it is evident that there are strong cultural rules at work, one cannot help but wonder whether feminist issues of power and control are also at work. On one hand, there can be the family influence of putting female offspring in their dutiful place where they then exercise passive aggressive control over caregiving situations. On the other hand, sisters may take over "leadership" as an approach to gain power in a world (and in her family) where being in-charge and being female are often paradoxical positions (Hirschman, 2006).

Being in-charge means that sister caregivers get to "call the shots" and have the final say in what aging parents' needs are and how best to address them. With sisters in

“power,” it makes one wonder what voice brothers have in caring for their aging parents. For the final factor of considering brothers’ contributions to filial care as unimportant or trivial, Matthews (1995) found that brothers were not necessarily more absent from caregiving conversations (and in some cases they took on leadership roles in filial care), but overall their contributions often were seen as minimal at best. However, their contributions were generally as gendered as their sisters’. Brothers typically provided stereotypical male-role types of services, like financial management and yard work while sisters typically took on the brunt of housework and tending to parents’ physical and emotional needs (Matthews, 1995; Matthews & Rosner, 1988). Matthews’ (1995) study was interesting in that brothers often followed suggestions of their sisters, but when they did not, sisters left brothers out in favor of proceeding in their own way. Possibly dismissing of brothers’ ideas in Matthews’ sibling groups was a way for sisters to maintain their power at least in their perception. But in the long run, it just underlines the gender ideals that still run rampant in American family life: that women’s place is in their home (and everybody else’s) and men’s place is, well, anywhere that is not the home.

Familial Roles

Another issue that sibling caregivers must deal with relates to their family roles. Importance of roles siblings played growing up was consistently present in much of the literature (Kahn & Bank, 1981; Matthews & Rosner, 1988; Russo, 2010a; Schulman, 1999; Wallhagen & Kagan, 1993). In addition to considering how gender played into roles that siblings took on in their families of origin, however, sibling roles were enacted

in other ways related to preexisting conflict and historical alliances held among family members. Oftentimes, siblings find themselves reenacting old ways of connecting with parents and with each other. Old competitions, rivalries, and relationship triangles may resurface; in many ways, these are based on how aging parents may continue to pick “favorites” and spotlight the differences among siblings (Matthews & Rosner, 1988; Russo, 2010a; Schulman, 1999). Sibling caregivers may find themselves vying for their parents’ attention and approval, or may just expect that they are going to be looked at as “goofball screw-ups,” for example. Kahn and Bank (1981) found that parents’ and other siblings’ views of each others’ roles were set in what was referred to as “frozen misunderstandings,” which were rigid ideas of identities and behaviors of individuals in families and based in family of origin interactions. What was implied was a sort of hierarchy of status related to how parents gave attention. Kahn and Bank believed that adult siblings could break free of frozen misunderstandings by confronting the “rigid arrangement of family roles” and gain equal status among siblings (p.2). Schulman (1999) noted that roles that people played growing up often present themselves in similar ways in other relationships as adults. In effect, those roles had a way of influencing characteristics siblings take on as independent adults. Therefore, if these roles could influence their adult identities, they certainly could impact their caregiving styles to aging parents. For example, adult siblings that were looked at as aloof or unreliable as children, may still be viewed by family members as dissociated from the family or irresponsible.

Sibling Factors

The third issue that impacts sibling caregiving relationships is the influence of individual sibling factors. Consistent ideas that surfaced in the literature were related to personality styles, number of siblings in the family, geographical proximity, competing obligations, and family organization (Matthews, 1995; Matthews & Rosner, 1988; Russo, 2010a). To begin with, personality is theoretically seen as something that is formed in childhood and becomes more solidified and defined in adulthood. Tests of personality, however, have been shown to have low to moderate reliability in test-retest examinations (Pittenger, 1993), meaning that personality is not a stable construct, and it does change for people. Nonetheless, adult siblings seem to view each other's personalities the same way they viewed them growing up. Matthews and Rosner (1988) found that siblings described their parents and each other as having the same personality styles as they did when they were kids. Moreover, they found that these perceptions "affected their relationships with one another and sometimes affected the style of involvement that the sibling was likely to use" (Matthew & Rosner, 1988, p. 191). Thus, siblings' perceptions of each others' personalities may hinder or bolster their ability to negotiate filial care of their parents.

Also, the number of siblings in a family impacted how siblings got along as well as their styles of interaction with each other. Again, Matthews and Rosner (1988) found that two- sibling caregiving systems were frequently best able to negotiate and equally share responsibilities. In addition, families with only two siblings sharing work often took on the two most intensive caregiving styles of involvement (Matthews & Rosner, 1988).

Theoretically, with a smaller number, there is less chance to be absent or inconspicuous without leaving the brunt of work to one person, as well as fewer opinions to juggle in decision-making. In contrast, bigger sibling caregiving systems may see more conflict (depending on factors such as their roles and personality types), and siblings may take on less involved caregiving styles.

Geographical proximity also was considered relevant to ways adult siblings negotiated care for their parents. Those who lived closest were not necessarily guaranteed to take on a routine style of caregiving, but they were more likely than those who lived out of town (Matthews & Rosner, 1988; Russo, 2010a). This component of sibling characteristics seemed to be influenced, however, by historical conflicts in the family of origin relationship, gender biases, and competing personal factors. Accordingly, brothers who lived out-of-town, those who were married with their own children, and those who were seen as the “black sheep” of families were most likely to be left out of sibling caregiver decision-making processes, more so than those who were in-town.

Competing personal factors were noted to be influential to sibling caregiving systems. Researchers found that spouses of sibling caregivers could hinder collaborative processes between siblings or could help to bolster them (Matthews & Rosner, 1988; Russo, 2010a). In addition, work schedules of siblings sometimes hindered them from participating in ways they may have preferred (e.g., routine caregiving). Still, Matthews and Rosner (1988) found that siblings were willing to participate in other consistent ways, even if work schedules got in the way.

Furthermore, perspectives of sibling caregivers on family structure was important to how they approached care of their parents and worked together. Siblings who maintained rigid stances on the nuclear family were less likely to be involved in more participatory ways of caregiving (Matthews & Rosner, 1988). In contrast, families who redefined the structure based on circular family systems, that included aging parents, were more collaborative (Ingersoll-Dayton et al., 2003). Thus, families willing to engage in positive feedback loops about structure of their families might be able to work in more balanced ways in caring for their aging parents.

Caregiving Typology

The caregiving styles that have been referred to, thus far, represent adult siblings' involvement in caregiving and patterns of providing filial care. Matthews and Rosner (1988) poignantly presented a qualitative examination of adult sibling caregivers' network of support. Their study contradicts the mass of literature that reports on just one individual as the "primary caregiver" for parents. What they found was that, although it seemed on the surface that certain siblings checked out or were uninvolved, they may have been involved in other ways, perhaps with different duties and styles of feedback to create equilibrium in their aging family of origin. Matthews and Rosner (1988) conducted a qualitative analysis and found five main styles of sibling caregiving involvement: 1) Routine – parental caregiving tasks were incorporated into siblings' daily lives; 2) Backup – siblings would make themselves present to support siblings who were routinely involved and could be counted on to follow instructions; 3) Circumscribed – siblings who were predictable in being able to help, but who had boundaries on what they could help

with; 4) Sporadic – siblings who would become involved at their own convenience; and, 5) Dissociation – siblings who were predictable in not being involved or counted on to help (Matthews & Rosner, 1988). They discovered that, based on sibling characteristics, proximity, competing obligations, perceptions of family organization, roles played in the family, and perceptions of parent care, sibling caregivers took on mainly one of the five roles.

Ingersoll-Dayton et al. (2003) took Matthews and Rosner's styles one step further and examined characteristics of sibling caregivers that actually collaborated with each other. Those that engaged in equitable sharing of caregiving for their aging parents had five characteristics: 1) they collaborated – by taking turns and dividing labor; 2) they redefined the caregiving system; 3) they enjoyed time together separate from aging parents; 4) they set aside time for planning caregiving; and, 5) they implemented suggestions from their aging parents. This model seems like an ideal, especially when thinking systemically. Individuals come together and through their interdependent process of negative and positive feedback, they decide what needs to be maintained in the family structure and what needs to be changed. These siblings are probably those that have come to grips with traditional and dated cultural beliefs about caregiving, that have come to terms with old conflicts and rivalries from childhood, and that have negotiated styles of contribution so that those siblings taking on routine caregiving styles have back up when needed and regular connection and communication with their siblings (Ingersoll-Dayton et al., 2003).

In contrast to this ideal of intra-family cooperation, many siblings feel alone with burden of care, and many are unaware of their personal issues that might be blocking sibling caregiving system connection (Dilworth-Anderson et al., 2002; Russo, 2010a). Russo (2010a) pointed out that many siblings feel obligated to take on roles as caregivers. However, when obligation is tied with factors such as old hurts, personality differences, long-distance, spousal differences, and gender roles, the pressure can build up for caregiving siblings, and the resulting stress and strain can take its toll.

It appears that what might impact the level of distress that some caregivers experience is their level of social support. Indeed, as mentioned earlier, caregivers often feel dissatisfied with social support they receive and experience reduced time in social activities separate from their caregiving roles (Dilworth-Anderson et al., 2002). Understandably, individuals providing care, day in and day out, with perceptions that they have complete responsibility for care recipients (and little time to care for themselves) may begin to feel burned-out, underappreciated, and resentful. This may be especially true when caring for aging parents in advanced stages of cognitive decline who can no longer recognize them. In fact, researchers have found that social support may have both direct and indirect positive influences on personal competence and well being (House 1985; Langford, Bowsher, Maloney, & Lillis, 1997). Thus, understanding the presence and function of social support in lives of caregivers for parents with dementia may be key in uncovering their perceptions of burden, competing obligations, and stress in their caregiving roles.

Social Support

Caregivers' experience of social support has been a topic of interest to researchers dating back to the 1970s. Yet, understanding social support and its functions has seemed to be a complicated process in itself. Since Sydney Cobb (1976) first formally defined social support, many other theorists have come forward to try to "streamline the definition" (House, 1985; Langford et al., 1997; Schwarzer & Leppin, 1991). With the number of different definitions and approaches to understanding social support, a lot of confusion has been created. Thus, it is important to differentiate the definitions, types, sources, and effects of social support.

Cobb (1976) defined social support as separate from instrumental (physical and/or monetary service), and consisting of connection with other individuals that provided intangible information received from relationships of mutual respect, and that encouraged independent behavior and empowered individuals. He believed that because social support was information, it was not something that could be measured in mass or energy, and therefore, material services did not count as social support. Additionally, he believed that instrumental support was tangible information that frequently manifested in the exchange of goods and services, but that fostered dependency, rather than autonomy (Cobb, 1976). Oftentimes, in dependent relationships, there can be an imbalance of power, which in Cobb's mind was a contradiction to the mutuality of respect and encouragement in socially supportive relationships.

On the other hand, another forefather of social support, James House (1985), took a broader look. He believed that social support implied an interaction between at least

two people, in which there was an expectation of reciprocity. House seemed to take Cobb's mutuality to mean that social support between individuals was based on the condition of exchange of support. Additionally, House (1985) theorized that social support included both intangible and tangible forms of social encouragement. In his view, the minimal condition was engaging in secure relationships with other individuals, and so any way of helping another was considered social support.

Still other researchers found that social support could be defined based on a number of preceding conditions. These conditions consisted of the presence of social networks (numbers of contacts and frequency), social embeddedness or integration (degree and connection), social climate (personality of environment), and relational content (roles of individuals; Langford et al., 1997; Schwarzer & Leppin, 1991). Thus, social support could be understood as a product of the varying levels of these conditions. By incorporating more concepts into understanding social support, it would seem that more depth could be discovered about its nature. However, determining the presence of social support in certain relationships is less clear. Consequently, it is easy to see how the broader the term gets, the more complicated the task of discerning the social support actually experienced by individuals, especially caregivers.

Thus, in defining the social support needed for caregivers, it may be beneficial to be specific about facets and types of social support that may be most relevant to those caring for aging adults with dementia. Both Cobb (1976) and House (1985) believed that for different situations with different kinds of people, certain types of social support would be more beneficial. Much of the existing literature on social support, however,

targets the experience of instrumental or material support (Hirdes & Strain, 1995; Ikkink & van Tilburg, 1998; Ikkink, van Tilburg, & Knipscheer, 1999; Tomita et al., 2010; Winslow, 1997). Focus on instrumental support may be due to ease in measuring material tasks and services and its supposed objectivity in being observed. As has been noted above, however, adult children of aging parents feel a lack of social support as indicated by their experience of burden, competing obligations, and lack of connection with other family caregivers, namely siblings (Adams, 2006; Alzheimer's Association, 2011b; Bertrand et al., 2006; Dilworth-Anderson et al. 2002; MetLife, 2011; Pinquart & Sorenson, 2003; Zarit et al., 1998). It seems that this perceived lack of support is related to the scarcity of intangible contributions of well being that can help ease the stress, burden, and competing roles that caregivers may take on. Therefore, exploring intangible types of support may give more information on the experience of social support in relationships between caregivers.

Types of Social Support

Since the definitions of social support are diverse, there are a number of types of social support to be considered. In the literature, there seem to be two main paradigms to conceptualize social support: the three-tiered approach and the four-tiered approach. The three-tiered approach has included three specific forms of social support, which have been differentiated from instrumental support. The first type of support in the three-tiered model has been labeled emotional support (Caplan & Killilea, 1976; Cobb, 1976). This type of support consists of information leading individuals to believe that they were cared for and that their needs for affection, nurturance, and connection were met. Additionally,

emotional support has involved intimate situations of mutual trust. The second type of social support has been labeled esteem support (Caplan & Killilea, 1976; Cobb, 1976). This type of support consists of information that leads people to believe that they are valued and esteemed. Such support helps to reaffirm individuals' sense of worth. Lastly, the third type of social support has been labeled network support (Caplan & Killilea, 1976; Cobb, 1976). Network support consists of information leading individuals to believe that they belong to a network of communication and mutual obligation. In network support relationships, information must be available to all in the support network and shared so that all members are aware of what other members know. The information that has typically been shared between individuals in network support consists of that which is related to the history of relationships in the network, to resources shared in those relationships (e.g., equipment, skills, and technical information), and to procedures for protection and prevention in the network. In the three-tiered paradigm of social support, then, the primary focus of assistance is on information sharing that validates the recipients in their feelings (emotions), self-perceptions (cognitive), and network actions (behavioral) of their caregiving experience. Moreover, this paradigm targets less concrete, but more essential, expressions of social support than purely the provision of material goods and services.

Although the four-tiered approach is comparable to the three-tiered paradigm, it seems to emphasize more reliance on concrete exchange of services. Similar to the three-tiered paradigm, the first type of social support that makes up this approach is emotional support (House, 1985). This type of social support includes the provision of empathy,

caring, love, trust, and concern for others. The second type is called appraisal support. It includes evaluative information that is affirming or allows for feedback and social comparison from family, friends, coworkers, and community providers (e.g., affirmations, feedback, and social comparison). This second type of social support has been described as an informative type of support in which information is given to others to validate them or otherwise assist in other's self-evaluating or engaging in social comparison. The third type, informational support, is similar to appraisal support in being informative, but is focused more on information about external resources, rather than self-reflective guidance. It includes advice, recommendations, and instructions to help individuals respond to situational demands. House (1985) described this type of support as giving information to others that they could use to help them cope with personal and situational issues. Finally, the fourth type of social support in the four-tiered approach is instrumental support. It involves concrete and direct assistance with specific tasks, including the provision of money, in-kind assistance, or manual labor and responsibilities. More specifically, it involves helping others do their work, take care of physical and external needs, and pay for things (House, 1985).

In summary, the four-tiered approach focuses on the concrete and or material representations of social support. Thus, instrumental support is an important part of this paradigm. Yet, it is important to note that House's (1985) four-tiered approach was based on his research on work stress and support. Specifically, he examined the presence of social support in the workplace, where finding concrete examples of shared support would be more appropriate than looking for the more complex relational connections of

support, such as in Cobb's (1976) paradigm. Nonetheless, many studies on caregiving have focused more on instrumental support (Hirdes & Strain, 1995; Ikkink & van Tilburg, 1998; Ikkink et al., 1999; Langford et al., 1997; Tomita et al. 2010; Winslow, 1997). Yet, caregivers continue to feel unsupported, presumably, when only provided with material and service assistance. Perhaps, a shift to a three-tiered paradigm that is relationally focused would shed more light on the dynamics characteristic of caregiving relationships.

Reciprocity of Social Support

Further exacerbating differences between the three-tiered paradigm and four-tiered approach is the argument for the conditional features of social support. Not only is its nature complex, but the process in which social support is delivered also is multidimensional. As mentioned above, researchers found similar but different methods of defining and categorizing types of social support. The basis of each of the definitions, however, was that social support was a one-sided provision of care, given wholeheartedly, without stipulation. Yet, the actual conditionality of social support has received mixed reviews.

In a review of social support, Avioli (1989) found inconsistencies about the nature of encouragement and assistance from siblings. From her study of the broad idea of social support, she found three basic themes that occurred in the literature on dyadic relationships, all related to the concept of reciprocity. She outlined three types of reciprocity: generalized, negative, and balanced. Generalized reciprocity was observed as being one-sided unconditional, in that these relationships were from one person giving to

another without expectation of receiving (Avioli, 1989). She postulated that generalized reciprocity was represented in relationships between spouses and children. Negative reciprocity was observed as one-sided conditional in that these relationships involved one person taking from the other with the expectation that the relationship would only persist based on what was provided. Negative reciprocity was represented in antisocial, short-term relationships. Lastly, balanced reciprocity was observed as two-sided and conditional, characterized by an expectation of the condition of mutual giving and receiving. For example, balanced reciprocity can be represented in healthy relationships of friends. Based on Avioli's analysis of reciprocity, she conceptualized the process of social support in sibling relationships. She contended that sibling relationships were like friend relationships that were formed on the basis of voluntary attraction and mutual interest, and grounded in an egalitarian status and connection (Avioli, 1989).

However, there seem to be problems with Avioli's (1989) conceptualization of siblings. Sibling relationships are not voluntary; they are given to us whether we like them or not (Cicirelli, 1995; Sanders, 2004). Individuals cannot divorce their siblings, even though some may decide to withdraw connection. By the same token, adult children may withdraw from contact and interaction with their parents. Yet, as researchers have found, eventually most individuals are drawn back to connect with their parents and siblings (Cicirelli, 1995; Matthews, 1995; Matthews & Rosner, 1988; Russo, 2010a; Sanders, 2004), if only because of obligations as executors of estates and power of attorney over parental medical care.

Additionally, Avioli (1989) supports her stance that sibling relationships are based on balanced reciprocity with the idea that siblings are socially condoned to withdraw physically and emotionally from each other. The idea is that siblings isolate from their family of origin to be independent from their brothers and sisters, so that they can be seen as more competent. Yet, her point of view is decidedly westernized, individualistic, and ignores the lifespan process of social support in the sibling relationship.

To her credit, Avioli (1989) does present a concept that she refers to as normative regulation. It refers to the balancing of support over time between individuals in long term relationships where they feel connected and emotionally bonded. Applying this concept, however, parental relationships also could be seen as those of balanced reciprocity-- the idea that parents have children in part so they can be guaranteed reciprocal care when they need it in their elder years. Therefore, parents may facilitate normative regulation in the process of raising their children, so that their children feel connected and motivated to take care of their parents in their older age. On the other hand, sibling relationships may share more generalized reciprocity when family members in the system facilitate normative regulation to support each other for the good of the whole.

Other researchers also view social support as being dependent on reciprocity. In a conceptual analysis of social support, researchers attempted to define social support (Langford, Bowsher, Maloney, & Lillis, 1997). They built their analysis on the assumption that social support was reciprocal in nature. However, their interpretation

seemed to be biased to a westernized assumption of preservation of individuality. These researchers noted forerunners of social support theory, yet they seemed to put their own spin on the nature of social support. For example, they referenced Cobb's (1976) review of social support, and paid particular attention to the interpretation of the type of social support that involves a "network of mutual obligation" (p. 96). Instead of interpreting Cobb's definition of mutual obligation (which was described in his 1976 article on social support) as meaning a network where information is available to all in the support network and shared so that all members are aware of what other members know, Langford et al. (1997) construed it to mean conditional reciprocity, or support that was given only with the expectation of receiving.

Similar to this idea of mutual obligation is what Ikkink, van Tilburg, and Knipscheer (1999) referred to as mutual interdependence. Mutual interdependence refers to the mutual endorsement of and actions toward the norm of adult children providing support to their aging parents in reciprocation for the care that parents gave them. In reference to Avioli's (1989) classifications, this social support between parents and their children would be typed as generalized (or altruistic) reciprocity – support given without condition. What appears, though, is a more complex understanding of familial social support: there is an eventual reciprocity expected down the road of life, where the support that was given to children was returned to parents in their elder years – more characteristic of a kind of delayed balanced reciprocity.

Regardless of classifications of support, it appears that social support given in the family of origin is indicative of the social support that will be given to parents in the elder

years by their children (Ikkink et al., 1999). Tomita, Sarang, Lee, Lee, Russ, and Noe (2010) found that the importance of mutual independence or delayed balanced reciprocity was represented in families, across cultures and extended across generations. They called this familialism. Additionally, regardless of culture, family members preferred informal support to formal support.

Other researchers found that beyond balanced reciprocity, a mobilization effect occurred (Schwarzer & Leppin, 1991). Researchers found that the manifestation of stress in the recipient of social support, mobilized different types of support responses. In some individuals, a stress/support condition of mobilization occurred. This happened when the recipient experienced stress, and social supporters were mobilized to provide support, resulting in good consequences and no further problems. Some individuals experienced a stress/illness condition of mobilization, in which recipients experienced stress without support, which moved to illness when they then received support, resulting in good consequences and reduced problems. Still, others experienced the illness-symptoms condition, in which recipients experienced stress with no support, then illness with no support, then subsequent symptoms of illness, which resulted in getting support. In this condition, the consequences were bad, but mediated by the support. Finally, individuals experienced a condition, in which stress and illness manifested concurrently, which provoked support to be given. In this condition of mobilization, consequences were mediated and recovery began immediately. Additionally, although stress and illness occurred at the same time, social support providers seemed to be heightened to service (Schwarzer & Leppin, 1991).

Schwarzer and Leppin's (1991) study is interesting in that it sheds some light on the possible differences in individuals' motivations to provide support. Beyond mere reciprocity, it seems that some social support providers must feel a palpable demand to provide assistance to family and friends in need. Specifically, with regard to adult siblings caring for their aging parents with dementia, Avioli (1989) found that siblings might disengage from connecting with and supporting each other because of violations of balanced reciprocity. For example, perhaps the siblings she studied experienced ill will in the family of origin relationship that made them reluctant to engage in generalized reciprocity and less apt to mobilize to assist. However, it is compelling to understand why some social supporters respond at the first signs of stress in their loved ones, and why others require more blatant proof of a significant need.

The intergenerational provision and receipt of social support by adult children to aging parents seems to be more complicated than simply looking at the reciprocity of giving and receiving support. Perhaps, processes at work relate more to the dynamic system of exchanges between family members and friends who are a part of the social support network. Based on data collected in the National Survey of Families and Households 1987-88, Eggebeen (1992) found four main patterns of intergenerational exchanges, including: 1) individuals who were not involved in familial exchanges; 2) individuals who gave advice, only; 3) individuals who received support only; and, 4) individuals who received and gave support. These patterns of support parallel Matthews and Rosner's (1988) typology of caregiving. Eggebeen's fourth pattern mirrors Matthews and Rosner's routine caregiver type – where caregiving tasks are integrated into day-to-

day routines and aging parents and adult children are part of a regular transaction of communication and support. The third and second patterns mirror Matthew's and Rosner's backup and circumscribed caregiver types – where caregiving tasks are specific and for a prescribed amount of time with a delineated amount of effort. The first pattern mirrors Matthews and Rosner's dissociation caregiver type – where caregiving exchanges do not take place because caregivers were predictably uninvolved in helping with caregiving tasks. Similar to Matthews' and Rosner's (1988) findings on family of origin roles and caregiving types, Eggebeen (1992) suggested that the type of support that was provided to aging adults was partly decided by exchanges learned in other times of family interaction. In a sense, old patterns of interacting when siblings were younger and living at home are often recapitulated into adulthood when the time comes to care for aging parents.

Complicating the understanding of the exchange of support even more is the possibility that the reciprocation of support is not necessarily quid pro quo. Hirdes and Strain (1995) investigated the balance of exchange as it related to the balance of power. They found that exchange of support was not necessarily eye-for-an-eye. Specifically, they found that the more sibling and friend supports that individuals had, the more likely they themselves were to be providers of support. On the other hand, those individuals who lived alone and who had smaller social networks were more likely to be receivers of support. The downside of this study was that it examined just the exchange of instrumental support (including housework, house maintenance, transportation, childcare, financial support, and personal care), and did not look at specifically at social support

(Hirides & Strain, 1995). Still, this study presented interesting findings about how potential caregivers to aging parents, especially those parents with dementia, might provide support. Hirides and Strain (1995) recommended that future research should examine the relationship between exchange and perceived wellbeing in network members.

Sources of Social Support

As has been established in the previous paragraphs, sources of social support can be found in various formal and informal network members. House (1985) suggested the spectrum of support providers may include such sources as: family of origin members, such as parents and siblings; current family members, such as partners or spouses; other relatives; friends and neighbors; supervisors and coworkers; and, community service providers or caregivers, community self-help groups, and community health or welfare professionals.

On the formal end of things, Winslow (1997) found that adult children used more formal supports than spouses did in care for aging adults with dementia. However, contrary to what might be assumed, she found that formal support (e.g., nurses, doctors, and other health-care professionals) did not predict a relationship between caregiver experience of overload and anxiety. In other words, the addition of some formal services to help spouses and adult children with the care of aging adults with dementia did not contribute to change in caregiver anxiety. This seems to ring true for the many other caregivers, too. Generally, families caring for aging adults in need of assistance have

preferences for informal supports from kin and friends, rather than support from formal services (Tomita et al., 2010).

Thus, other researchers have focused on the importance of informal support, in particular the assistance from family and friends. House (1985) saw family and friends as crucial to fostering success in the network because they were the most frequently named as support sources. Additionally, he saw them as important because they were the best preventive forms of social support and “if effective, they preclude the need for more formal support or treatment” (p.24). The preventative impact of informal supports is a critical point, especially in today’s remedial and reactive society. Rather than responding to need with expensive and intrusive formal care support, individuals could be assisted through preventive social support that stems from established networks (e.g., families, friends).

House (1985) suggested that effective formal support prevention programs (to deal with stress and other mental health issues) could increase their benefit by incorporating the social support from informal support sources. He noted that informal supports had been shown to be effective in reducing stress, improving health, and buffering the impact of stress on health. In particular, social support from informal care may be more beneficial than formal assistance because it is based on mutual respect and egalitarian relationships. Thus, support may be seen as more meaningful and accepted when coming from a respected source and when it is based on spontaneous actions rather than a contracted role of serving based on an employed position. Moreover, informal

support may seem more genuine and therefore may be more effective in buffering stress, strain, and other psychological experiences (House, 1985).

To the extent that social support from family members and friends is crucial to helping individuals cope with and address stressful situations, adult sibling caregivers to aging parents with dementia could benefit from social support received from their brothers and sisters. First, healthy sibling relationships are based on a foundation of , egalitarianism, rather than a hierarchy (Cicirelli, 1995; Sanders, 2004). Ideally, then, in their egalitarian sibling relationships there would be mutual respect and empathy. Thus, caregiving siblings would respect each other and work to understand each other's strengths in the caregiving process.

Second, caregiving siblings' collaboration in caregiving processes would work as a preventative service for their aging parents with dementia, rather than having to rely on costly formal care. Adult siblings in the caregiving network would be sharing in a three-tiered social support process, based on exchange of emotional, informational, and esteem support. This would give caregiving siblings the validation, motivation, and general love and affection needed to persevere, problem-solve, feel motivated, and feel control to contribute to the wellbeing of their aging parents. Therefore, being supported could help caregivers contribute even more. Similarly, an advantageous cycle of social support between caregiving siblings and their aging parents could be created.

Impact of Social Support

It is easy to imagine the possible positive outcomes from a cyclical family network of support, including validation, motivation, and overall wellbeing that could

ensue among all family members. House (1985) believed that social support could have an impact on wellbeing because social support meets basic human needs for security, social contact, approval, belonging, and affection. In addition, he believed that it could influence the experience of interpersonal pressure and tension by bolstering motivation to be a part of social groups, to be accepted by peers, and to experience self-acceptance and value. Indeed, both House (1985) and Cobb (1976) found that the impact of social support had buffering effects such that individuals who experienced high life change, and who had high social and psychological resources, fared better on indicators of mental and physical health.

Cobb (1976) conducted a review of the literature on social support. His review examined social support and its facilitative impact on various life changes including pregnancy and birth, adulthood milestones (e.g., college, employment, and marriage), hospitalizations, illness recovery, alcohol abuse, aging, bereavement, and threat of death. Cobb (1976) found that in most studies, social support worked to help individuals cope better and recover faster, need less medication and hospitalization, and experience less negative physical symptoms.

More recently, Langford et al. (1997) suggested that social support could have positive effects on coping, decreased depression, personal competence, positive affect, stability, self-worth, satisfaction, and wellbeing. In their study, they found positive relationships between control and social support. Specifically, they discovered that individuals' levels of perceived expectancy of control in situations was based on how much they believed they were supported.

Hence, social support between siblings may work to increase their mental health and wellbeing, thereby facilitating more physical health and life satisfaction in caregiving networks. In addition, feeling empathy, empowerment, and care from fellow sisters and brothers could work to bolster perceptions of control in caregiving processes. Consequently, understanding the dynamic interplay between communication and collaboration in caregiving sibling networks is essential to uncovering sibling perceptions and experiences of connection and social support in systems of care for aging parents with dementia.

Family Systems Approach

A systems perspective can provide an appropriate model for understanding and addressing the issues that sibling caregivers face. Family systems theory is a model that stresses the importance of gaining knowledge about the interconnections of individuals and the problems that exist by looking at family members in relation to each other, not as individuals alone (Hecker et al., 2003). It is the synergy of interdependent members' behaviors and influences that make the whole family system unit. Typically, individuals' concerns have been examined as something related to their internal abilities to regulate their thoughts, emotions, and behaviors (Nichols, 2004). Therefore, from an individual perspective, psychological problems exist in the minds of individuals (Hecker et al., 2003). Yet, in family systems theory, individuals' problems exist in interconnections between family members that are part of systems. In order to understand mental health of individuals, the nature of connection and communication in the family must be understood because individuals cannot be fully understood separate from the context of

the family system (Cox, 2010; Hecker et al., 2003; Nichols, 2004). As Hecker et al. noted, “the success of the family depends on the existence and connection with other family members... the study of the family must begin with the relationships, and interactions among family members” (p. 42).

Thus, when caregivers to aging parents with dementia feel stress and burden, it can be conceptualized not as only a primary caregiver issue, but rather a family issue. Connection and support for one caregiver could likely influence other caregiving siblings in the system. “According to family systems theory, all members of the family system are interconnected, and a change in one part of the system means a change for the whole system. Therefore, it would be expected that other members of the family, and not just the primary caregiver and [care recipient] would also be profoundly affected...” (Gan & Schuller, 2002, p. 312). As has been noted previously, researchers have demonstrated the need to understand problems that sibling caregivers experience in parent-caring systems, rather than from the perspective of a primary caregiver member (Matthews & Rosner, 1988). These researchers found that it was through the interactions of all siblings in a family that decisions were made about whom, how, and when care of aging parents would take place. Thus, caregiving responsibilities and stresses are viewed in the context of the whole family, not understood just as the experience of one caregiver.

Key Points

Family systems theory is based on the work of Ludwig von Bertalanffy (1968), Norbert Weiner (1954), and Gregory Bateson (1972). In order to describe the interactions and relationships of objects in a system, von Bertalanffy theorized that seemingly

unrelated parts or events could be seen as interrelated and part of a greater system. Weiner described the nature of communication among parts of a system. Bateson, however, brought von Bertalanffy's (1968) and Weiner's (1954) ideas together to describe the relationships between people in a family (Hecker et al., 2003). He called it family systems theory.

Family systems theory involves many different terms and concepts that can be used to understand the complexities of families. Yet, there seem to be four basic points to consider when examining family systems. First, individuals in systems experience interdependence. Specifically, any system is an organized whole and objects within the system are necessarily interdependent, so elements in a system are affected by what happens to other elements in the system (Cox, 2010; Hecker et al., 2003). Elements that exist in the family system each have specific purposes, functions, and goals. These elements include: 1) objects (family members), 2) attributes (e.g., goals, energy, attitudes, ethnicities, and family characteristics), and 3) relationships (communication between family members; Hecker et al., 2003). Thus, it can be surmised that each sibling in the family system is essential for understanding the greater phenomena that impact care of aging parents with dementia.

Second, the whole is greater than the sum of its parts (Hecker et al., 2003; Nichols, 2004). Unlike a machine that is made up of parts that are mutually exclusive and serve a specific function that can make or break its functioning, living systems operate based on synergistic qualities between members of a system (Nichols, 2004). This idea is referred to as nonsummativity. In nonsummativity "the relationships among family

members are greater than the simple contribution of individual family members” (Hecker et al., 2003, p. 46). Consequently, patterns of caregiving may be understood as dynamic interdependent functions between all caregiving siblings in the system rather than the voice of just one caregiver.

Third, systems are composed of subsystems (Hecker et al., 2003; Nichols, 2004). Family systems exist within the systems of society, politics, and economics, as well as within neighborhoods, communities, states, and countries. They are subsystems of greater societal factions. Within families are smaller subsystems, including sibling systems. Therefore, understanding the influence of smaller systems like the sibling network is integral to understanding the larger family system (Namyslowska & Siewierska, 2010; Nichols, 2004).

Fourth, patterns in a system are circular, rather than linear (Hecker et al., 2003). More specifically, family systems theorists and practitioners believe that problems in families are multi-causal and reciprocal, moving in cyclical ways. Moving circular patterns are homeostatic mechanisms that maintain stability of family patterns and these are referred to as feedback loops (Hecker et al., 2003). Feedback is defined as the input from each family member that results in complex and systems related output (Hecker et al., 2003; Nichols, 2004). Feedback can be positive or negative. Positive feedback loops reinforce themselves. That is, when change occurs it is maintained such that the status quo is not continued in lieu of change (Hecker et al, 2003). Therefore, changes that are made in the system are accepted and old ways are put aside, theoretically speaking. Negative feedback loops work to obstruct system change and reinforce the status quo;

when change occurs, family members will behave in ways that revert back to the way things have always been. Therefore, change is rejected and the status quo is maintained. The goal is to balance stability and adaptability in the system (Hecker et al., 2003; Nichols, 2004).

For example, to examine sibling caregiving that focused on harmony in relationships as opposed to conflict, Ingersoll-Dayton et al. (2003) investigated patterns of collaborative sibling caregiving relationships. They found that equitable sharing of caregiving consisted of two main pieces of feedback: 1) collaboration, and 2) process functions. In collaboration, siblings made decisions together about how to take turns doing tasks for their parents and how to divide labor. In this way, siblings may have to use negative feedback loops to set boundaries for things they are capable of doing and those they are not, but also may use positive feedback loops to support change in the family of origin roles they played growing up, such that new, more productive roles can be created to help their parents and other caregiving siblings. In process functions, siblings worked to redefine the caregiving system, set up time to enjoy together (separate from their parents and caregiving duties), initiated time to reconfigure and plan care for their parents, and integrated their parents' suggestions in decision-making processes (Ingersoll-Dayton et al., 2003). Again, using the feedback loop model, siblings might begin to change their perceptions of what the family is through positive feedback loops that support a change from nuclear family based to a family that includes grandparents, aunts, uncles, and cousins. However, in maintaining important family values, using a

negative feedback loop to help implement suggestions and wishes from aging parents may work to preserve the respect and autonomy of elders in the family.

Etiology

From a family systems perspective, when sibling caregivers experience depression or caregiving strain, it is not merely intrapsychic breakdowns of those caregivers that lead to mental health concerns, but rather a failure of the family system unit to function appropriately and prevent those caregivers from mental and physical deterioration. Family systems theorists see problems in families as indications that “something is not working effectively within the family structure or process” (Hecker et al., 2003, p. 51). Problems may arise from structural symptoms such as hierarchy, boundaries, subsystems, and rules, as well as from process symptoms such as how family members interact and communicate (Hecker et al., 2003).

Just as adult siblings must reorganize to accommodate needs of aging parents in declining health, other parts in the system must adjust to accommodate caregiving siblings. As Dilworth-Anderson et al. (2002) described it, dependent on race, ethnic background, and gender, those “other parts” of the system may be all of the siblings in a family, or may include other family members and close friends as informal social supports. In addition, the system may extend to more external systems for formal care including adult daycare, home healthcare, community mental health services, physical therapy, and telephone assurance supports (Dilworth-Anderson et al., 2002; Wan, 1987; Zarit et al., 1998). As might be intuitively expected, researchers found that the more support caregivers perceived, the less strain and depression they felt with regard to their

roles in providing care to their aging parents (Dilworth-Anderson et al., 2002; Zarit et al., 1998). Thus, the addition of support – even formal – may offer a reorganization of caregiving systems and adaptation to change for the better of the whole.

Addressing problems in family systems involves maintaining equilibrium in the feedback loops of family communication (Hecker et al., 2003). Consequently, there must be a balance of change (positive feedback) and maintaining family norms (negative feedback). It is important to note that negative and positive do not imply bad or good communication. Instead, they each, at any given time, act to reject a change (for good or for bad) or act to reinforce a change (for better or for worse). Families, where siblings and aging parents work together to redefine their roles, divide tasks equitably, communicate openly, and integrate ideas of all involved, may exemplify systems in which equilibrium between maintaining important family ideals of supporting elders is balanced with change of stereotypically female roles of caretaking to be more equitably dispersed among sisters and brothers. Moreover, researchers have found that without any intervention, family system functioning has continued to be troublesome and did not change over time (Gan & Schuller, 2002).

Recommendations for Understanding the Caregiving Process

It is necessary to explore perceptions and experiences of connection and social support between caregiving siblings to aging parents with dementia from a family systems perspective (Cox, 2010; Feinberg, Solmeyer, & McHale, 2012; Namyslowska & Siewierska, 2010). Thus far, researchers have predominantly focused on primary caregivers' reports of their perceptions and experiences, rather than examining caregiving

processes from the point of view of the caregiving sibling system. Most times, adult children take on caregiving responsibilities and tasks (Cantor, 1992; MetLife, 2011). Often, problems reported by caregiving siblings of parents with forms of dementia relate to their experiences of stress and burden in managing and carrying out those duties (Alzheimer's Association, 2011a; Eldercare Partners, 2011; Pinquart & Sorenson, 2003; NAC et al., 2011; Wallhagen & Kagan, 1993; Zarit et al., 1998). In addition to caregiving, competing obligations of personal lives and family of origin concerns (Eldercare Partners, 2011; HIP & NAC, 2005; MetLife, 2011; Rosenthal et al., 1996; Russo, 2010a) and absence of social support (Adams, 2006; Dilworth-Anderson et al., 2002) can cause a great deal of stress and strain. What must be understood are the dynamics between siblings in caregiving systems that contribute to experiences of sibling connection and support (or lack of connection and support) in the care of their parents with dementia.

Yet, there is a lack of information on sibling relationships from the family system point of view (Cox, 2010; Feinberg et al., 2012; Namyslowska & Siewierska, 2010). Gan and Schuller (2002) used family systems theory as their theoretical model to understand the impact on the caregiving family network when caring for a family member with a brain injury. They found that family members identified more distress than those caring for individuals without brain injuries. Thus, the impact of responsibility of caregiving for someone who was cognitively incapacitated caused elevated stress in caregiving systems. It is not such a stretch, therefore, to anticipate that adult children caring for parents with dementia would be affected similarly. Understanding the impact of caregiving on all

members of the family system is the next logical step. In fact, researchers have recommended that future research should investigate experiences of caregiving from a family systems approach (Gan & Schuller, 2002; Perlesz, Kinsella, & Crowe, 1999).

The social benefit for conducting inquiry on this topic would be: 1) to garner understanding of how sibling connection and social support manifest in situations where siblings are caring for aging parents with dementia; 2) to shed light on roadblocks that hinder families from working together in end-of-life care of their loved ones; 3) to inform mental health practitioners of important issues that families face when collaborating in dementia care; and 4) to help adult caregiving siblings to become aware of family resources that may serve to reduce burden, stress, and loss of control in the experience of caregiving for aging parents with dementia.

Conclusion

In summary, the incidence of forms of dementia is on the rise in the U.S., and more and more aging adults are requiring their children to help care for them and maintain their wellbeing in their elder years. Although individuals prefer informal care provided by family and friends, professional formal services have been made available to help primary care providers with instrumental care tasks. Especially with regard to those providing caregiving for adults with dementia, it is often the adult children who take on the primary responsibility of care. However, little is known about the caregiving process of adult siblings in the system of care because most of the literature has been focused on the experiences of primary care providers. Yet, researchers have found that there are varying levels of caregiving involvement by caregiving siblings, from routine to

dissociation (Matthews & Rosner, 1988), which has received little attention in current research and which may provide greater understanding of demands, stresses, and needs for caregiving siblings to aging parents with dementia. What has been found in the literature is that caregivers to aging adults with dementia are burdened and stressed, juggling competing obligations, and feeling a lack of connection and social support. Exploring the caregiving sibling system from a family systems paradigm may help to reveal the phenomena that contribute to situations of collaborative care, and to those of companionless burden.

CHAPTER III

METHODOLOGY

The purpose of this study was to explore the perceptions and experiences of sibling connection and social support between caregiving siblings to aging parents with dementia. There were three primary objectives of the proposed study. The first objective was to explore perceptions and experiences of sibling connection in caregiving sibling systems in order to understand differential circumstances that siblings had while caring for parents with dementia. The second objective was to investigate degree of social support related to dementia caregiving processes that was perceived and experienced among siblings in caregiving sibling systems. The third objective was to understand emergent themes that clarified caregiving siblings' perceptions and experiences in dementia caregiving systems. In order to understand the caregiving sibling system, the researcher obtained information on the experiences of caregiving from sibling dyads in families that were caring for aging parents with dementia – specifically, those who were participating in the care of one parent who had dementia and whose spouse was no longer living or part of the provision of care.

Examining perceptions and experiences of each of the siblings in the family from a family systems framework represented a divergence from typical models that looked at primary caregivers, only. In fact, some researchers have stressed the importance of

understanding all siblings' perspectives in family systems in order to understand the nature of family problems (Namyslowska & Siewierska, 2010). Because of the newness of this approach in looking at caregiving sibling systems that help aging parents with dementia, the researcher used a qualitative model. Specifically, a method of phenomenological inquiry was used to analyze and interpret findings of each sibling interview in families who were caring for parents with dementia. In using phenomenological analysis, researchers have recommended five to six cases as reasonable sample sizes (Smith & Osborn, 2007). The current study explored perceptions and experiences of siblings from five families.

Research Questions

There has been a gap in the literature on caregiving for aging adults with regard to perceptions and experiences of adult siblings taking care of their aging parents with dementia. It was unknown what phenomena of caregiving sibling systems affected perceptions and experiences of sibling connection and social support (or lack of sibling connection and social support), especially with regard to intense tasks of caring for parents with dementia. Accordingly, there were three research questions in this study:

- 4) What phenomena emerge that clarify caregiving siblings' perceptions and experiences of sibling connection in dementia care?
- 5) What phenomena emerge that clarify caregiving siblings' perceptions and experiences of social support in dementia care?
- 6) What themes emerge that clarify the dementia caregiving system for adult sibling caregivers?

Research Design

Overview of Phenomenological Methods

To answer the research questions, the researcher used the exploratory methodology of phenomenological inquiry, specifically interpretive phenomenological analysis, a qualitative approach to understand lived experiences of individuals in everyday situations from the standpoint of individuals' personal accounts of objects, events, and experiences (Giorgi & Giorgi, 2003; Smith & Osborn, 2007). The primary aim of this methodology is to explore and understand the meaning, or essence, of the phenomena under study. In the current study, it was used to explore the phenomena of sibling connection and social support in the relationships of siblings caring for aging parents with dementia.

As a philosophical model, it was made distinct as an analytical process by Edmund Husserl in the late 20th century (Giorgi & Giorgi, 2003; Pringle, Drummund, McLafferty, & Hendry, 2011). He believed that with such an approach, he could help differentiate the basic psychological concepts that underlie individuals' perceptions and experiences, and thus bolster a more consistent and accurate use of psychological phenomena by psychologists. In addition, he theorized that phenomenology could help investigate individuals' lived experiences more accurately than positivistic models or empiricism could (Giorgi & Giorgi, 2003). Thus, he devised a three-step approach to study the emergence of phenomena and their ultimate essence. Step one was to adopt a perspective of phenomenological reduction; step two was to employ the method of free imaginative variation to explore the possibilities of meaning of the phenomena; step three

was to describe the basic fundamentals of the objects, events, or experiences under study in order to determine the essentialness or essence of phenomena (Giorgi & Giorgi, 2003).

In step one, adopting a perspective of phenomenological reduction involves observing phenomena exactly as they are presented, with no interpretative meaning assigned to them (Giorgi & Giorgi, 2003). Objects, events, and experiences of individuals are reduced to purely what the participants are experiencing, rather than getting muddled by the researchers' positings of meaning. In this way, researchers take whatever is given to be a phenomenon, and "make no commitments to the existence of the given within the reduction" (Giorgi & Giorgi, 2003; p. 240). Basically, the idea is that researchers adopt a mindset that is open to what the possibility might be, knowing that there are various interpretations to an observed phenomenon.

In step two, employing the method of free imaginative variation to explore the possibilities of meaning takes the first step a bit further (Giorgi & Giorgi, 2003). Free imaginative variation is the process of observing the transitions in meaning in the data, and then determining the possible meanings of these transitions. In this step, researchers engage in the process of breaking down the data into parts through making meaning discriminations, which ultimately end with the determination of meaning units.

Finally, in step three, the constituent meanings are extracted from the data to explicate the essentialness or essence of the phenomena and are compared with the original data to describe the structure of the phenomena under study (Giorgi & Giorgi, 2003). In this step, researchers explore the psychological essence of individuals' objects, events, and experiences, rather than trying to find a universal meaning. Again, it is the

individuals' lived experiences and thus idiosyncratic accounts that are considered crucial to understanding the essence of the phenomena.

The steps of phenomenological inquiry, described above, are based on several core principles. First, understanding of phenomena is determined by individuals' accounts of their lived experience (Giorgi & Giorgi, 2003). Moreover, this knowing is made up of two types of understanding: one, understanding as empathy or identification with participants, and two, understanding as meaning-making of participants' experiences. Second, participants' own streams of consciousness and depictions of everyday life represent the data that are involved in the analysis and interpretation processes. Third, critical checking and rechecking of the meanings and constituent parts of the meaning structure with participants' original responses is essential to accurately determining the essence of the phenomena (Giorgi & Giorgi, 2003; Smith & Osborn, 2007). Fourth, the understanding of phenomena is an idiographic process, rather than a nomothetic process, and every effort is made to understand the idiosyncratic nuances of individuals' experiences. Fifth, it is recognized that while this phenomenological approach aims to gather knowledge about individuals' experiences from an emergent open-ended point of view, some bias is expected because researchers' own experiences with and knowledge of the phenomena under study. To control for this, scholars suggest that researchers bracket past knowledge about phenomena, in order to explore participants' experiences more freshly (Giorgi & Giorgi, 2003; Pringle et al., 2011).

Critique of Phenomenological Methods

Although phenomenological inquiry can be particularly beneficial when examining novel situations, there are limitations to using this approach. For example, although phenomenology offers a model for seeing events in a more complete and in-depth way, findings are unable to be generalized because of the subjective nature of responses (Pringle et al., 2011). Especially when data are cross-sectional, it may be difficult to determine if patterns and themes are representative of the respondent, let alone to the population. Yet, the depth of meaning that can emerge in studying a phenomenon can create a descriptive picture that may help in understanding the context of quantitative data that have been collected on a phenomenon (Pringle et al., 2011). Thus, phenomenology helps to bolster quantitative data, as well as qualitative information.

Another criticism of phenomenological inquiry is its interpretive quality, especially when using interpretative phenomenological analysis (IPA; Pringle et al., 2011; Smith & Osborn, 2007). In IPA, researchers are charged with two tasks: 1) observing what emerges, and 2) making sense of what manifests. However, in both tasks, a certain amount of researcher bias could develop because of researchers' differences in perception and in their styles of interpretation. Consequently, researchers' interpretations could be misleading in reporting results (Pringle et al., 2011). However, it is precisely this acknowledgement of researchers' presence in the knowledge-making process with participants that underlies the IPA approach – it emphasizes the importance of the researcher in getting into the personal world of participants (Smith & Osborn, 2007).

Despite these potential limitations, a phenomenological approach was a relevant fit to the current study on caregiving siblings' perceptions and experiences of sibling connection and social support in the sibling system of care for aging parents with dementia. Smith and Osborn (2007) noted that phenomenological analysis "is a suitable approach when one is trying to find out how individuals perceive the particular situations they are facing...especially useful when one is concerned with complexity, process or novelty (p. 55)." Following from that, the current study sought to understand the complexities of the caregiving sibling systems for aging parents with dementia. In addition, because of the novelty or newness of looking at caregiving from the perspective of a caregiving system, rather than primary caregivers, phenomenological analysis was an appropriate choice for exploratory research, such as the proposed study.

Participants

Five sibling dyads participated in the current study, equaling a total of 10 siblings. Participants were recruited from families of aging parents with dementia in a Midwest urban city. They were sampled through convenience sampling, and specific notification about the study occurred through word-of-mouth interactions with the researcher's peers, including family members, friends, and colleagues. Additionally, recruitment flyers were posted at community and memory care centers for aging adults with permission from facility directors. Upon establishing verbal connection with potential participants (receiving an email message or phone call from those who were interested in the study, and who met the recruitment criteria detailed below), the researcher sent recruitment letters that detailed specific parameters of the study (see Appendix A). In it was a request

for participation and descriptions of the purpose and objectives of the study, possible incentives for participation, amount of time and type of involvement required, nature of the questions that were asked, location of the study, as well as logistics of informed consent, confidentiality, audio-taping of interviews, disclosure of voluntary participation, and the contact information of the researcher and Office of Research Compliance at UNCG. Participants who read over the recruitment letter and agreed to participate emailed or phoned the researcher to coordinate interview times for them and fellow caregiving siblings. Upon meeting participants in their homes, and otherwise self-selected secure, safe, quiet, and distraction-free location, the researcher again went over details of the study and the interview, provided information about the researcher and appropriate contact information, and the parameters of informed consent. The researcher asked participants to sign consent forms before any data were collected.

The researcher recruited participants based on several criteria. First, participants who responded to the recruitment letter had to be adult children of individuals who were receiving care for their dementia. Second, adult children had to be currently caring – specifically, they were participating in the care of one parent, rather than both. Third, to avoid the complexity of the interlacing of multiple family member caregivers, this study recruited adult siblings who had only one living parent. All sibling dyads were caring for one parent without the assistance of a living parent, except for one family. Fourth, while it was preferable that all adult siblings in families were willing to participate, a more refined criterion was used that at least two siblings (sisters and/or brothers) would be

willing to participate. In this study, four sister-brother dyads and one brother-brother dyad agreed to be interviewed.

To date, there have been various findings for caregiving siblings with regard to race, culture, and age (Alzheimer's Association, 2011a; Dilworth-Anderson et al., 2002; HIP & NAC, 2005; Matthews & Rosner, 1988; MetLife, 2011; National Alliance for Caregiving, 2011; Russo, 2010a). In the current study, demographic data (e.g., gender, race, age) were collected only to describe the sample and were not used to exclude participants or considered as variables in data analysis. The rationale for not using demographics as recruitment criteria was that by opening the investigation to all demographic types the analysis would uncover emergent themes undefined by certain demographics, and thus uphold the novelty of investigating caregiving siblings from a family systems paradigm. Participants completed a four-page demographic questionnaire (see Appendix B) after informed consent was obtained, and before the interview began. The demographic questionnaire requested information on gender, race/ethnicity, age, education level, employment status and hours, relationship status, family structure of immediate family and family of origin (if applicable), gender and age of parent to whom they were providing care, proximity to parent, the numbers of hours caregiving, frequency and type of contact to parent, types of caregiving responsibilities, and type of caregiving involvement or role siblings play in caregiving.

Procedures

Upon meeting participants in their homes, and otherwise self-selected private, secure, safe, quiet, and distraction-free locations, the researcher went over the details of

the study and the semi-structured interview, provided information about the researcher and appropriate contact information, and the parameters of informed consent (see Appendix C). Participants had the opportunity to ask questions for clarification and then sign consent forms to participate in the study. After signing the informed consent form, participants completed the demographic questionnaire (as described above). Once it was completed, participants engaged in 120-minute, face-to-face, semi-structured interviews about their perceptions and experiences of sibling connection and social support in caregiving sibling systems as they cared for their aging parents with dementia. The format of the interview was based on typical formats of phenomenological inquiry and analysis (Smith & Osborn, 2007), as well as based on knowledge that the researcher had regarding the in-depth nature of participant responses on the study topic. After completion of the interview, participants received a packet of information (created by the researcher) detailing community resources available to help participants and their families to address their needs and concerns related to caring for their aging parents with dementia (see Appendix D). The packet included helpful articles and checklists, as well as contact information of local and national organizations to aging adults with dementia. Additionally, follow up emails were sent to participants thanking them for their contribution to the research and inviting them to review their transcripts for accuracy. Total estimated time for caregiving siblings' participation was three hours (including recruitment, interviews, and follow-up correspondence).

Interviews were documented through audio recording and note-taking by the interviewer. Siblings in families were asked a structured set of questions, but some

questions varied depending on unique responses to each sibling's questions. In regards to confidentiality, although siblings' interviews were compared, they were confidential between each sibling and the interviewer. This means that siblings were interviewed separately and the interviewer did not share what was said between siblings. Additionally, because interviews were audio recorded, the researcher maintained confidentiality of recordings by keeping them stored on the researcher's computer, which was password protected, and for which only the researcher had access. Data was transcribed in part by the researcher, and in part by a contracted transcriber. However, before the transcriber received files, she completed a research confidentiality agreement. During transcription, the transcriber coded any persons identified in the transcript with an arbitrary code, as directed by the researcher. In this way, confidentiality was ensured because identifiers were removed. Additionally, an independent reviewer had access to coded transcripts (without identifiers). However, before she had access to transcriptions, she also completed a research confidentiality agreement. The researcher erased digital audio files of interviews after they were transcribed, coded, checked for quality assurance, and data analysis was completed. Informed consent documentation and transcriptions are being kept in a locked filing cabinet at the researcher's home office.

The intended location of interviews was participants' homes. Other researchers using phenomenological inquiry recommended conducting interviews in safe, comfortable, and familiar places, like individuals' homes (Smith & Osborn, 2007), because allowing participants to participate in interviews in these familiar locations may help them feel more secure and relaxed. Most participants elected to meet in their homes.

However, participants in Family 4 and Family 5 chose to have their interviews at their place of business, in a coffee house, and at the researcher's place of business, respectively. In order to establish the privacy of participants' interviews, the researcher ensured that interview spaces were quiet, secure, and free from outside intrusions or distractions.

In addition to the project disclosure that participants received in the recruitment letter, they also received an informed consent form (see Appendix C) that detailed the goals and objectives of the interview, amount of time and nature of involvement in the interview, the limits to confidentiality, the procedures and uses of audio recording, contact information for the research team, and request for signature indicating that they agreed to the participate under the parameters disclosed in the informed consent statement. Upon participants' signing of the informed consent form, recording of the interview began. Participants received their caregiving information packet (see Appendix D) at the conclusion of the interview.

Instrumentation

The current study used a semi-structured face-to-face interview format as the instrument to collect and describe participants' lived experiences and perceptions caring for aging parents with dementia. As was mentioned earlier, phenomenological inquiry and analysis typically has used an interview format to facilitate personal accounts of participants' experiences related to the topic of interest. Interview questions have been designed to encourage participants to talk openly about the topic of interest, with minimal directives from the interviewer. Nonetheless, Smith and Osborn (2007) recommended

determining overall areas to center interview questions, and then to ask them based on a funneling technique that elicits both general and specific points of view from participants. This approach also has allowed for gradual ease into interviews and time to build trust and rapport with initial broad level questions, so that there is comfort in answering in-depth type questions later on. As a result, general questions of caregiving sibling personal involvement in care and personal issues were asked initially, then family system issues discussion points were discussed, and finally questions about experienced and perceived sibling connection and social support among caregiving siblings were asked, getting deeper and closer to the phenomenon of interest.

This study employed a systematic, open-ended, and emergent phenomenological analysis of transcribed data. After recorded interviews were transcribed, the researcher engaged in a process of methodical step-by-step analysis of participants' responses. The aim was to explore emergent themes and ultimately describe the essence of participants' meanings of the phenomenon under study. A detailed description of the data analysis process is below. Fundamentally, it involved a process to describe and understand the idiosyncratic nature of the phenomenon for each case.

Finally, a data analysis team was used to review and make sense of data collected through interviews. Although such a research team approach to data analysis is not typically required when conducting phenomenological analysis, the researcher in this study believed it would bolster validity and reliability to have an independent reviewer available to examine data. Therefore, the researcher engaged in analysis of data with one

independent reviewer as a way of achieving consensus on results and providing quality assurance.

Interview Procedures

Prior to beginning the 120-minute semi-structured interviews, participants completed brief demographic questionnaires (see Appendix B) to help the interviewer in guiding the participant through the interview. It also helped the participant warm up to the interview process. In conducting interviews, the researcher used a researcher-generated list of interview questions and prompts to elicit participants' personal accounts of the topic under study. Smith and Osborn (2007) suggested that questions be in a format that funnels them from general to specific. In the current study, the researcher's interview schedule began with general questions about personal activities that participants engaged in, the type of care they gave their parents, and the type of involvement that siblings had in general. Then, the researcher moved to more specific questioning related to the family systems issues that came up when caring for their parents with dementia. Next, prompts were given to explore the perceived sibling connection and social support (or lack of sibling connection and social support) that caregiving siblings experienced in the sibling caregiving system. The interview ended with invitations for participants to discuss other aspects of their experiences in the caregiving system.

Below is a list of the different types of questions, from broad to specific, that were used to facilitate and guide participants during the interview:

Warm up questions (broad, introduction questions):

What kinds of things do you do on a daily basis?

Who are the family members in your life that you connect with?

How are you involved with care for your parent with dementia?

How is your relationship with your parent?

Who are your siblings and how do they help?

In general, how are your relationships with your siblings?

Transition into specific questions:

How was it decided about how you would be involved with care of your parent?

How is what you experience and/or perceive of your sibling relationship like or not like what you have always experienced since growing up?

Probe questions (key questions):

What helps you out in caring for your parent with dementia? Who helps?

How do you get help?

What involvement of formal support (e.g., counselors, therapists, nurses, doctors, direct-care workers, etc.) have you experienced?

Tell me about your experience of sibling connection from your siblings while caring for your parent?

Tell me about your experience of social support from your siblings while caring for your parent?

What do you think about it?

How do you feel about it?

What barriers are there to caring for your parent? How do your siblings help or not help?

Ending questions

What other things do you wish that we could have talked about?

What was your experience during the interview?

What information will you take away from this experience?

Data Management and Analysis

Informed consent and permission to audio record was obtained at the beginning of meetings and before interviews started. Once interviews were complete, audio files were uploaded digitally, and the researcher secured the audio files of the interviews by keeping them on her computer that was password protected, and for which only the researcher had access. Next, the researcher sent the contracted transcriber the audio files to be transcribed. She did this by uploading digital files to *Dropbox*, a secure file sharing service. Before the transcriber had access to files in the *Dropbox*, she completed a certificate of confidentiality (see Appendix E) in which she agreed to keep secure and confidential participants' data. Additionally, during transcription, the transcriber coded any persons identified in the transcript with an arbitrary code. Participants' names were changed to a coded name based on the first names of famous musician pairs (e.g., siblings Zoey and Matthew from Family 1 were named after musician duo Zoey Deschanel and M. Ward of music band *She & Him*). In this way, confidentiality was ensured because identifiers were removed. Also, an independent reviewer had access to coded transcripts (without identifiers). However, before she had access to transcriptions she completed a

research confidentiality agreement (see Appendix E). Audio files were destroyed as soon as the researcher verified transcripts, data were coded, and data analysis was complete. Transcriptions will be held for duration of 5 years, but kept confidential and secured in a locked file cabinet in the researcher's home office.

Trustworthiness of data analysis and interpretation. In addition to ensuring that data were managed in secure and confidential manners, the researcher took measures to make certain that trustworthiness of data analysis and interpretation was demonstrated. The researcher used Shenton's (2004) four-step process to establish trustworthiness of data results including, 1) demonstrating credibility, 2) providing means of transferability, 3) showing dependability, and 4) presenting confirmability.

Credibility. Establishing credibility in qualitative research is the act of accurately recording the phenomena that are being investigated (Shenton, 2004). There are several methods to producing credibility including employing operational methods of conducting the data analysis and interpretation, triangulation, tactics to ensure honesty, reflective commentary by the researcher, and member checks. In the current study, the researcher used bracketing and step-by-step data analysis procedures to employ operational methods of conducting the data analysis and interpretation. Giorgi and Giorgi (2003) suggested that bracketing be done as a means to ensure participants' experiences are taken as close to how they were accounted, and to bracket past knowledge so that researchers can look at the phenomena as if for the first time. Therefore, the researcher, as well as the independent reviewer, participated in a bracketing exercise that consisted of two parts. Part one involved meeting to discuss the importance of bracketing and the specific

strategies involved. Following accepted procedures (Giorgi & Giorgi, 2003), members of the research team were instructed to independently write down their reflections on the study topic (i.e., expectations and biases). These instructions were discussed prior to the researcher and independent reviewer undertaking their independent bracketing. One week later, the researcher and independent reviewer met for part two of the bracketing exercise to discuss potential biases and expectations in the data analysis process. Bracketing themes are summarized in Appendix F. Some themes that researchers identified were not found in a majority of the families' stories. For instance, a theme of "congruency in stories" came up for both researcher and independent reviewer, indicating an expectation that siblings would have similar perspectives on their caregiving experiences as well as on growing up in the family of origin. However, as will be discussed in the paragraphs below, siblings often disclosed different viewpoints of their involvement and their siblings' involvement in the family and system of care. In addition, some bracketing themes surfaced in the data analysis. One example is the theme "roles" that indicated an expectation that siblings would take on roles in the family and in the system of care that were similar to roles they assumed while growing up. As will be reported in the results, all family members described their siblings' roles growing up in the family and reported that these roles had been maintained in adulthood and caregiving contributions. The researcher and independent reviewer paid close attention to match up themes with what participants actually said in order to capture their stories as they were reported (Giorgi & Giorgi, 2003). One sibling exemplified this in her interview by saying "well, I can only say that I think the relationships are pretty much the same as they were"

(SHARON.51.27-51.28; Seaman, 2014j). Thus, even though bracketed themes may represent themes that emerged in the siblings' stories, every effort was made to ensure that themes aligned with what participants were actually saying.

The researcher also employed triangulation, which is a process of collecting data from multiple informants to corroborate the data that are collected (Shenton, 2004). Specifically, the researcher collected information from participants in two formats: demographic questionnaire and semi-structured interviews. By doing so, it allowed for a check of reliability in how participants responded in different formats. Participants responded congruently with demographic questionnaire and the semi-structured interview. In addition, the researcher collected data from sibling dyads, which yielded perspectives to corroborate the perceptions and experiences of sibling dementia caregivers. Having the responses of the sibling dyad helped in finding reliability in responses because, for the most part, participants in each dyad had convergent stories about the nature of caregiving in their families. In one sibling dyad, the sister and brother had divergent perspectives about the dementia caregiving process in their family. These incongruencies are discussed further in Chapter 4.

Additionally, Shenton (2004) recommended implementing tactics to ensure honesty in responses. One way that the researcher fostered openness and honesty in participants' responses was by communicating unconditional rights for participants' to refuse to participate in the study. For example, the recruitment letter and recruitment script (see Appendix A and G) and the informed consent form provided the disclaimer that participants may withdraw from the study at anytime without penalty. Additionally,

the semi-structured format of interviews provided a foundation of openness that supported the idiosyncratic nature of each participant's story and a nonjudgmental and accepting stance of the researcher. Using the approaches discussed above ensured honesty in participants' responses, and thus maintained credibility in trustworthiness of data analysis and interpretation.

Further, it was suggested that the researcher engage in reflexive commentary about the data collection and analysis process (Shenton, 2004). In this way, the researcher evaluates the process of data collection, analysis, and interpretation and reflects on preliminary impressions. In this study, the researcher made process notes through the data collection, analysis, and interpretation process that provided contextual perspective from which to understand study results. Process themes have been summarized along with main study themes in Chapter 4. Additionally, as mentioned above, the researcher and independent reviewer met throughout the data analysis phase to ensure unbiased theme discovery. Again, the methods of reflexive commentary described above helped to ensure credibility in handling and interpreting the data.

Also, Shenton (2004) suggested that researchers conduct member checks. At three points in the study member checks were conducted. At the first point, the researcher asked participants what their experience was during the interview and what other topics they wished to discuss that we had not covered. Asking questions like the aforementioned created a dialogue about the process of data collection and clarification of questions that were asked and responses given. The second point at which member checks were conducted was after the interviews had been transcribed and data analysis themes were

organized. At that point, participants had a chance to read their responses and give clarification and provide their thoughts and elucidations on the aggregated results of the thematic analyses and interpretations. At the third point, the researcher sent participants electronic files of the completed study for their review and feedback. In each of the check points, emphasis was on whether participants believed that their words matched what they intended to convey, as well as being able to verify theoretical inferences from the thematic analyses (Shenton, 2004). And so in conducting member checks, employing operational methods of conducting the data analysis and interpretation, triangulation, tactics to ensure honesty, and reflective commentary by the researcher credibility and trustworthiness will be maintained in handling data.

Transferability. In addition to the establishment of credibility in trustworthiness of the data analysis and interpretation, it has been recommended that researchers present transferability (Shenton, 2004). This is the act of establishing the representativeness of the results to wider populations. While the data collected in this study were qualitative and represented small and particular environments and people, it is possible that the findings may be informative and relevant for practitioners working with familial dementia caregivers. In order to support transferability to participants, Shenton (2004) recommended that “sufficient contextual information about the fieldwork” be provided (p. 69). Thus, the researcher provided detailed descriptions of sibling dyads so that future readers of this research (e.g., dementia caregivers, practitioners, and researchers) would comprehend the contextual factors in which to understand the results of this study, and thus make transfers to their own fields of work, if applicable. By providing contextual

information, the researcher has promoted transferability and trustworthiness of the data management and interpretation.

Dependability. Establishing dependability was also important to trustworthiness of data analysis and interpretation (Shenton, 2004). This is certified by systematically and thoroughly describing the consistent and purposeful method of completing the data collection, analysis, and interpretation. Thus, in the current study, the researcher used a documented step-by-step plan to recruit and collect data (see Appendix G and the interview questions discussed earlier in this chapter), as well as specific data analysis and interpretation steps (see Appendix H and the data analysis procedures discussed below). By using these steps consistently, dependability and trustworthiness data procedures were maintained.

Confirmability. Finally, confirmability was demonstrated to ensure trustworthiness in data management and interpretation. Shenton (2004) recommended the importance of providing objectivity of results or what he calls confirmability. Like establishing transferability of qualitative findings, confirmability can be difficult because of the subjectivity of qualitative data. The goal is to ensure that the results are indicative of participants' experiences and perceptions, and not the "preferences of the researcher" (Shenton, 2004, p. 72). Again, as described above, the researcher ensured objectivity by implementing bracketing steps with an independent reviewer to evaluate any potential bias that would obscure data analysis and interpretation of results. Additionally, other triangulation steps of establishing credibility (as described above) were employed to

verify confirmability and overall trustworthiness of data collection and analysis procedures and interpretation.

Data analysis. Once the transcripts were created, the data analysis began. The analysis process was done one case at time. The researcher began the process from a stance of psychological phenomenological reduction, meaning that the experiences of individuals were taken exactly as they presented themselves without assigning any interpretive meaning to them. The researcher began the data analysis by reading and rereading an entire transcript for one case (Giorgi & Giorgi, 2003; Smith & Osborn, 2007). This ensured that the researcher had a general sense of the transcript in its entirety. Then, the researcher read through the transcript placing marks where a transition in meaning was apparent, thus creating meaning units (Giorgi & Giorgi, 2003). Smith and Osborn (2007) described a process of making comments of interest or significance in the left margin of the transcript in this step. In this study, the researcher highlighted material with different colors to indicate meaning transitions in the transcript text. Next, she went back through transcripts and made meaning notes and/or phrases to describe the highlighted meaning transitions.

Following that, and with the same phenomenological mindset, the researcher transformed the meaning transitions and/or comments of interest and significance into psychologically sensitive expressions or emerging theme titles (Giorgi & Giorgi, 2003; Smith & Osborn, 2007). Once all meaning transitions and comments were titled, themes were ordered, first chronologically and second according to analytical connections between themes or clustering of themes (Smith & Osborn, 2007).

Subsequently, the researcher produced a table of 18 superordinate themes ordered by four superordinate clusters (Smith & Osborn, 2007). Clusters of themes were given titles that represented the superordinate themes. In a table, under each superordinate cluster were listed all the themes that fell under that particular cluster. Each theme that was listed had an identifier to aid in finding the original data in the transcript that was connected to the theme. The identifier was distinguished by the transcript identification code, page number, and line that the data were on. For instance, if a specific point came from data found on the transcript MATTHEW at page 14, line 5, the identifier would be “MATTHEW.14.5.” As mentioned above, participants’ names were changed to a coded name based on the first names of famous musician pairs.

Once this process was completed for the first transcript, the researcher and independent reviewer convened to come to consensus on the themes found and superordinate themes that emerged. Once consensus was reached, the researcher and independent reviewer repeated the process for other caregiving sibling transcripts for the other siblings in the family. Consensual analysis was conducted on transcripts of the first two families and the final family. Eventually a final table of superordinate themes was made for each family.

After each family of siblings had been analyzed for themes and final tables of themes were created, a large family cross-analysis of themes was made. In this final study table, themes were selected based on two main criteria: 1) frequency that themes appeared in the cases, and 2) richness and how themes illuminated other aspects of the phenomena under study (Smith & Osborn, 2007).

Statement of meanings. The final step in the data analysis process was writing up the results and final statement of meanings. In this step, the researcher translated themes into written narrative and reflections (Smith & Osborn, 2007). Here the emergent phenomena of caregiving siblings' experiences and perceptions of connection and social support were reflected upon and synthesized to provide a web of association between the different themes that emerged and the actual reports of participants.

Summary of Methodology

This study aimed to understand the emergent phenomena of adult siblings' experiences and perceptions of sibling connection and social support in relationships of those caring for their aging parents with dementia. The methodology of phenomenological inquiry was used to make sense of developing themes. The researcher recruited siblings through word-of-mouth sampling, and targeted families with sisters and brothers who were part of family systems of care for their aging parent who had dementia. Informed consent was obtained, 120-minute semi-structured interviews were recorded, and interviews were conducted in sibling dyads of participating families. Subsequently, recordings were transcribed and analyzed through parameters of phenomenological inquiry. Finally, results were described, interpreted, and synthesized to establish relevance to families, formal care providers, counselors, and researchers interested in topic of siblings caring for parents with dementia. Discussion of results is presented in Chapter 4.

Pilot Study

In spring 2013, a pilot study was conducted to test the methodology for the current research. The pilot study and the full study (that will be discussed in Chapters 4 and 5) were approved and found to be compliant with federal regulations and policies by the UNCG Institutional Review Board (see Appendix I). In order to test the proposed inquiry on sibling connection and social support of adult siblings caring for aging parents with dementia, the researcher conducted a pilot study on a family consisting of one sister and one brother. The pilot study served as a trial run of the interview process and data analysis procedures with one family. Following the data collection and analysis, the researcher reported results of the phenomenological inquiry, as well as feedback on the experience and methods obtained from family members. Additionally, the researcher reflected on her own experiences and made note of the challenges and changes that may need to be made in streamlining the proposed inquiry. Through this “test run” of procedures, logistical aspects of the main study were evaluated for feasibility with the targeted sample.

Sampling

Convenience sampling was used to recruit pilot study participants. Specifically, the researcher provided information about the study and contact details to colleagues, family members, friends, and acquaintances. The researcher’s family members connected with friends of theirs who were interested in being participants in the study. Subsequently, they provided the researcher with their friends’ email addresses and phone numbers to contact them. The researcher contacted the participants by phone and used the

Email and Phone Recruitment Scripts to outline the information and directives for the study (see Appendix G). After providing information over the phone, seven families agreed to participate in the pilot study. However, six of the seven families were considered ineligible. In two families, the parent being cared for passed away before the study could be conducted, and so they did not meet the recruitment criteria of currently caring for an aging parent with dementia. In two other families, the sisters and brothers declined to participate because of the stress that was occurring in the family. Finally, in two different families, the sisters of the brothers that I interviewed declined to participate, and so those interviews did not meet criteria for the study. Consequently, one family consisting of a sister-brother dementia caregiving pair from a suburban town in Connecticut participated in two semi-structured interviews that were conducted for the pilot study.

Procedures

The researcher contacted each sibling individually, read over the recruitment script, and answered initial questions about their participation in the project. After questions and concerns were addressed, each sibling proposed meeting at the same friend's house for their separate interviews. Before the phone discussion with the researcher, the siblings had decided together that they would like to meet in a neutral space, which they believed would be safe, secure, and free from distractions and intrusions. Additionally, they received permission from their friend prior to the phone conversations. The researcher inquired about the security of the environment and was

assured that it was a safe and secure space. Finally, the participants and the researcher agreed on separate meeting times and scheduled the interviews.

Interviews were conducted over two afternoons, with the sister's interview being first, and the brother's interview on the following day. Siblings were interviewed separately in the dining room of a friend's house at a large table, with large comfortable chairs. The atmosphere was quiet, comfortable, and free from distractions.

For each interview, the researcher began by providing verbal and written information about herself and the nature of the study by means of the recruitment letter and the informed consent form. Additionally, she disclosed the necessity to audio record the interviews, parameters of confidentiality, and how she would maintain secure and confidential care of their recorded interviews and subsequent transcripts. Participants were informed that they could withdraw from the study at any time. After reviewing study information, participants were asked to sign the informed consent form, and then the audio recorder was turned on.

The researcher used the Voice Memo feature on her iPhone 4S to record the interviews. Her iPhone was password protected, and was a safe and secure voice recording device for the scheduled 90-minute interviews. The researcher had tested the Voice Memo recording feature on data she had collected for other projects, and found it to be a reliable and streamlined way to collect audio data.

Once interviews began, the researcher asked participants to complete demographic forms. She then began the interviews with warm-up questions, such as who are the family members in your life that you connect with and how are you involved with

care for your parent with dementia? Next, she asked transition questions like how was it decided about how you would be involved with care of your parent, then probing questions like what helps you out in caring for your parent with dementia, who helps, and what is your experience of sibling connection and social support from your siblings while caring for your parent? The interview finished with ending questions that inquired about other things that participants wished to discuss, what their experience was during the interview and what information would be taken away? Also, participants were asked about questions that seemed confusing or anything missing, and generally any changes they would make to the interview format. The researcher made notes of any process observations and feedback throughout the interview sessions and at the end to get clarifications and feedback from the participants.

Upon completion of the interview, the researcher provided each sibling with a packet of information (see Appendix D) they could use to help each other, themselves, and their parent. Specific pieces of information included signs and symptoms of MCI and forms of dementia, treatments and care for dementia, list of organizations and agencies (local and national) specializing in dementia care, handout of new approaches to caregiving (family systems point of view and collaborative caregiving), and important articles and reports that might be helpful. Additionally, the researcher made sure that they had copies of the informed consent forms and recruitment letters, which detailed the researcher's contact information.

Once these two interviews were completed, the researcher uploaded the audio files of the interviews from her secured iPhone to her secured, password protected, laptop

computer, so that the files could be played on her audio software. For the pilot study, the researcher transcribed the two interviews, using a word-processing program. During transcription, the researcher coded any persons identified in the transcript with an arbitrary code. In this way confidentiality was ensured because identifiers were removed. Once the information was transcribed, the researcher sent transcriptions to the participants to receive their feedback and clarification. Each sibling participant emailed the researcher with no clarifications, but with positive feedback about how much they enjoyed their time talking about their experiences and perceptions of the caregiving process. However, the sister made note that a name was identified in the content of her transcript. The researcher found the identifying information and recoded the identifier to maintain the confidentiality of the participant. Additionally, she sent a cleaned copy of the sister's transcript to her.

Results

One family consisting of one sister and one brother from a suburban town in Connecticut was recruited for the pilot study. These participating siblings reported that they were caregiving for their aging mother who was 77 years old and who had been suffering the concurrent effects of having dementia and a brain tumor. In this family, sister and brother shared in the caregiving of their mother with their father who was currently still living with their mother in the family home.

Both participants completed the demographic questionnaire at the start of the interviews. Both answered the questions fully except for the question about who makes up your family of origin. For each of them, they included their family of origin relatives

in their list of immediate family members, which may account for why they did not feel it necessary to re-list the names of their family of origin members. They listed themselves as white. The 44-year-old sister reported that she had completed an Associate Degree as her highest level of education; she was employed full-time, and married. Her 46-year-old brother reported having a Bachelor's degree, being unemployed, and single. The sister reported that she lived 35 miles away from her mother, and the brother reported that he lived with his parents. The sister reported that her frequency of contact with her mother was twice per week by phone, while the brother reported 24 hours per day and week of face-to-face contact with his mother.

It was anticipated that the interviews would last for one to one and a half hours. In actuality, however, the sister's interview was approximately three and a half hours in duration, while her brother's interview was approximately four hours in duration. At about the one and a half hour mark during each interview, the researcher checked in with each participant to alert them that the interview was reaching its end, and both sister and brother expressed their desire to move forward. The brother stated, "And it's nice to talk about it too. Because I really haven't been able to talk about it. I don't have to talk about it with my father. He knows very well" (WILLIAM.37.10-37.11, Seaman, 2013b). Additionally, the brother disclosed, "Oh I'm open. It's been fun... I have nothing to do" (WILLIAM.41.12, Seaman, 2013b). Halfway through the sister's interview, she called to check in with her husband to let him know that she wanted to continue the interview longer and that she would run late getting home.

Generally, interview process feedback from the participants was positive. In an email follow up to the transcripts that were sent, brother disclosed:

It was good to talk about it then. Yeah, a month already. I am now starting to think about other things and projects again. Waiting for more warm weather... it was fun to talk. I am adjusting to life without such a load and house cleaning and just getting on with stuff I like to do (William, personal communication, April 29, 2013).

Brother referred to life “without such a load” because his mother passed away three days after our interview. The sister emailed her response to the interview and said:

Thank you so much for your wonderful attention, your caring, support, and interest! I am very honored that the Universe arranged for us to meet you, and just exactly when my brother and I needed it most! Thank you very much for the transcript hard copy, I really, appreciate it since I don't yet have the updated technology to easily download or print it myself... The transcript looked great... I felt very empowered reading it over because I felt I had been completely authentic and I stuck by all of it, not wanting to change anything. This is quite a departure from the old me of yore when, as someone who had no center, I would have been very ashamed of my feelings and descriptions and would have felt crippling guilt for my disloyalty to my family in telling things as I see them... Thank you eternally, Megan, for letting me be me and encouraging me to feel my own feelings and therefore be able to heal them and move on with my life. (Lauren, personal communication, June 4, 2013)

Again, the sister referred to the timing of the interview as being a blessing in relation to the passing of her mother only days after we met.

A look at content analysis. As for the content analysis of themes, because the transcripts were each about 100 pages long, the data analysis took several weeks to complete. The researcher followed the protocol of the Interpretive Phenomenological Analysis (IPA; Smith & Osborn, 2007), which called for several readings of each

transcript, making of meaning units, categorizing of themes, organization of superordinate themes, quality assurance check from the independent reviewer, and then creation of final table of family themes. For the pilot study, over 75 unique themes were found in the combined analysis of sister's and brother's transcripts. Examples of themes included caregiver observations of the caregiving process, caregiver proximity, caregiver decision making, past experience with dementia care, caregiver reflection on mom's condition, skepticism in formal care, formal care expenses, formal care involvement, laughter, existential/spiritual experience, caregiver coping, important relationships, information recommendations in caregiving, emotional support in caregiving, legal information in caregiving, reflection on personal identity development, caregiver needs, caregiving responsibilities, sibling relationships, caregiver involvement, family of origin relationships, family of origin stories, past and current family roles, personal reflections and miscellaneous thoughts, metaphor, misunderstandings, caregiving approach, difficulty in caregiving, distrust/mistrust of others, rage/anger, feelings of being overwhelmed, formal care negative feedback to family, criticism, barriers to involvement, diagnosis, frustration/disregard, and communication breakdowns.

Themes seemed to fall into two family system categories of feedback: 1) positive feedback – creating change in the caregiving system, and 2) negative feedback – maintaining family status quo. A total of 11 superordinate themes clustered under the family system categories, and can be seen in Table 1 below.

Table 1

Final Table of Family Themes – Pilot Study Family

Family Category:	Positive Feedback Themes (things that created change in the family):
Superordinate Themes:	1) Brother: Decision Making - Individual (Autonomy or Initiative) 2) Brother: Initiative Taking - Collective 3) Sister and Brother: Spiritual/Existential Intimacy 4) Sister: Independence/Autonomy 5) Sister: Identity 6) Sister: Relationships
Family Category:	Negative Feedback Themes (things that maintained the family status quo):
Superordinate Themes:	7) Brother: Role Maintenance (Identity) – collective 8) Brother: Identity Formation (Identity) - individual 9) Brother: Social Intimacy 10) Sister: Mistrust 11) Sister: Role Confusion

After several iterations of combing through the data of each transcript and describing the emergent themes, the researcher found family themes emerged related to feedback loops of communication, in which themes of support and connection were embedded. For instance, the brother indicated the importance of collective initiative-taking in caring for his mother. He said:

...we had to help her and one day, she wanted to get up in the middle of the night to go to the bathroom and, you know, we heard this clump. And it woke us up 'cause it was, I don't know, it was 3 in the morning, or something. And we "what the heck was that?" And so we went to look and she'd fallen and she'd wacked her head on the bench or something that was near the bed because her knee gave out. (WILLIAM.13.23-13.28, Seaman, 2013b)

The brother referred to the collective and supportive process of helping mom out. In addition, the sister reported that the relationship changes with her brother helped to change the responses she had to her family of origin. She said:

But interestingly enough um, around the age when I was 8, my brother was 10, we found a way to be friends and be allies that she could not penetrate and my father, nobody could penetrate because we found our own little way. And in fact we still use this. (LAUREN.29.11-29.14, Seaman, 2013a)

She referred to a breakthrough in communication that they developed in their childhood as a result of game they made up with two toy animals they were given. Each of them found an identity in their toy animal as well as finding their voices to communicate with each other. Both sister and brother discussed how that foundation of communication had changed into a network of communication that helped them to express themselves without criticism from their parents. They no longer had the toy animals, but they maintained the voices that their animal personas had adopted. Both described their form of communication as the way sisters and brothers should live – in harmony.

Additionally, to the surprise of the researcher, themes of adult development seemed to emerge. As the data analysis proceeded, recurring ideas of trust, autonomy, initiative, identity, and intimacy kept coming up – ideas that seemed particularly developmental and mirrored Erikson's stages of psychosocial development (Ivey, Ivey, Myers, & Sweeney, 2005). These developmental themes made up the superordinate themes under which the unique themes clustered. However, a theme of spiritual/existential intimacy emerged in sister's and brother's interviews. This theme was not indicative of Erikson's stages, but perhaps could be understood better from more

holistic paradigms such as the model of the Indivisible Self (Sweeney & Myers, 2003), in which the spiritual self is the center from which all other aspects of the self are brought forth.

Summary. The purpose of the pilot study was to test out the data collection and analysis procedures and to garner feedback about the process. For the most part, the data collection process went according to plan except for a few changes that were made to accommodate the participants who were eligible to be a part of the study. Those changes and limitations are discussed below.

Study Modifications

Based on the results of the pilot study, the following modifications were made to the main research study. First, the sampling frame was expanded in three important ways to include recruitment of potential participants: 1) connected to community centers and health centers, 2) living in the Eastern region of the U.S., and 3) including sister-brother, sister-sister, and brother-brother dyads. To start, because of the temporal challenges of participants dropping out of the pilot study because their parents passed away, as well as participants declining to participate because of family of origin conflict or for other reasons, it was difficult to find participants that met all the recruitment requirements. Additionally, it was decided that the main study would expand recruitment from focus in the Midwest region to families throughout the Eastern U.S. Finally, instead of concentrating on all siblings in a family, and at the very least a sister-brother dyad, the sampling frame was limited to two siblings per family, but opened the participation to all kinds of sibling dyads. By expanding the sampling frame, it was hoped that a large

enough pool of participants would volunteer to participate so that participant attrition and other uncontrollable factors could be accounted for, thereby ensuring a minimum of five families' full participation in the main study.

Second, the researcher expanded the interview length from a maximum of one and half hours to a maximum of two hours. In the pilot study, it was learned that caregivers' interviews can stretch in duration well beyond the proposed time limit of one and half hours. In fact, the sister and the brother in the pilot study had interviews that lasted approximately four hours each. Because every hour of interview time took about five hours to transcribe, it was not feasible to transcribe the expected five to 10 sibling dyad interviews in a reasonable time period. Also, it would be challenging at best to recruit a sufficient number of participants who would be willing to sit for three- or four-hour interviews. Thus, the decision to modify the expected interview duration to two hours gave participants extended time to discuss their perceptions and experiences of caregiving, but also maintained a reasonable interview length for transcription and analysis.

Third, it was decided that multiple interview formats be presented to participants, including face-to-face interviews, phone interviews, and video interviews. The expansion of accepted interview formats came from the challenges that were presented in interviewing siblings that lived out of the sampling frame, thus making it difficult to arrange a face-to-face meeting. In the main study, all participants were given the options of meeting in person, on the phone, or online for their interviews.

CHAPTER IV

RESULTS

The current study involved interviews with five sibling dyads of families living in the Midwest who were in the process of caring for a parent with dementia. Ten siblings (two from each family) completed demographic questionnaires and participated in semi-structured interviews of their experiences and perceptions of dementia care, including their perceived sibling connection and social support. In cross-family analysis, four superordinate clusters and 18 superordinate themes were found in all participants' narratives. In addition, process data were compiled with regard to participants' experiences in their interviews, and the researcher's personal experience in the data collection process. Finally, member checks were conducted through email follow up on participant responses. Results are presented below.

Demographic Questionnaire

Each participant completed a 27-item questionnaire that covered questions about their parents with dementia, their siblings, and themselves. Questions related to gender, race/ethnicity, age, education, employment, relationship statuses, parent demographics and connections, numbers of family members, and their levels of involvement in caregiving and the family system. Participants' responses to the questionnaire have been summarized in Appendix J. A total of 10 siblings participated – belonging to four sister-brother dyads and one brother-brother dyad. Thus, 60% of the sample identified as male.

Four of the five families identified their race/ethnicity as White and one family identified as Asian/Native Hawaiian or Other Pacific Islander. Participants had a mean age of 56.7 (ages ranged from 44 – 66 years old, $SD = 8.08$). All participants had earned at least a bachelor's degree, and 60% had a master's degree or higher. All were still working in some capacity (mean of 33.7 hours per week; $SD = 16.17$; range 0-55), except for one participant who reported being "retired." The majority of participants (60%) were married, 30% were divorced, and 10% were single (never married).

Participants reported information about their parents who were receiving dementia care (see Appendix J). In three out of five families, the parent with dementia was the mother, with an average age of 85.8 ($SD = 7.57$). They reported that their parents had been experiencing dementia symptoms for a mean of 4.03 years ($SD = 3.43$; range from 1-10 years), but their involvement in helping their parents had been a little longer, with a mean of 5.08 years ($SD = 3.15$, ranging from 1.5-12 years; see Appendix J). Types of dementia caregiving responsibilities reported by participants ranged from practical concerns of Activities of Daily Living (ADL; e.g., meals, medical management, laundry, and transportation) to emotional support. The most frequently occurring dementia caregiving tasks included ADLs, visits to parent, financial management, having meals together, and providing emotional support to and checking on the parent's wellbeing. In addition, participants reported on the types of involvement they had in dementia care. The researcher observed that participants answered questions similarly about caregiving responsibilities and caregiving involvement/role. Only two out of 10 participants differentiated tasks from involvement and reported general roles in caregiving

involvement as “regular” or “sporadic.” However, four of ten participants described their involvement as adding support through listening, patience, and engagement, which was differentiated from caregiving responsibilities.

Participants discussed caregiving in relation to proximity to their parent with dementia. Forty percent of participants lived “within 6-20 miles,” 30% lived “within 21-100 miles,” and 30% lived “more than 100 miles away” from their parent with dementia. On the other hand, participants reported their siblings’ proximity to parents was a little closer, with 19% living with or within five miles of their parent, 38% living within 6-20 miles, 26% living within 21-100 miles, and 17% living more than 100 miles from parents. Participants responded in different ways to the question of their sibling proximity, such as specific miles or minutes to their parents. Therefore, the researcher corrected for the discrepancy by categorizing their responses in one of the four categories: “living with or within five miles,” “within 6-20 miles,” “within 21-100 miles,” and “more than 100 miles.” For instance, if a participant said their sibling lived 45 miles away, then that sibling was considered to be in the “within 21-100 miles” category of proximity. One family had a unique situation in which their mother spent equal periods of time with her seven children, three of which lived in Manila, Philippines, with the other four dispersed throughout North America. For this family, proximity from the parent ranged from living with them to being overseas. In this family’s case, the researcher categorized the best case scenario of “living with or within five miles” for proximity. As for the other families living only in the U.S., their distance to parents varied from being out-of-state to parents living with them. Additionally, within-state

participants and their siblings were separated from their parents with dementia by an average of 31.13 miles ($SD = 38.30$, ranging from 3-200 miles from parents).

Despite differences in participants' and their siblings' proximity to parents, participants reported that their personal contribution to caregiving was a mode of 4 hours/week (the mode was used because two of the participants reported 24/7 care to their parent, which skewed the average; see Appendix J). Additionally, caregiving contacts with their parents included face-to-face visits, phone calls, text messaging, and emails. The average frequency of contacts from participants to parents was 2.6 contacts/week ($SD = 3.81$, Mode = 1, ranging from 0-13).

Each family in this study had a mean of five adult siblings ($SD = 2.92$, ranging from 2-10 siblings per family; Appendix J). Interestingly, participants reported more hours of personal involvement in caregiving per week than their siblings. They rated their perceptions of their siblings' caregiving involvement, separate from their own (Mode = 4 hours/week). Using a 10-point Likert scale ("1" = not involved at all, to "10" = routinely and consistently involved), participants rated their siblings' level of involvement in caregiving as a mean of 7.24 ($SD = 2.90$; ranging from 0-10), and reported that the modal number of hours per week that siblings spent on dementia caregiving was a little more than two ($M = 5.81$, $SD = 11.40$, ranging from 0-42 hours weekly). Types of caregiving contributions from siblings ranged from sharing responsibilities in caring for their parents to contacts with parents and each other (e.g., in-person, by phone, and/or online). Nevertheless, the top five contributions from siblings in the five families included visits

to parents, business/financial management, emotional support, meals together, and no contribution at all.

Participants described family members whom they felt supported by in the dementia caregiving system and the type of support these family members provided (Appendix J). Most participants (eight out of 10) reported their perceptions of siblings' social support as varied and dependent on the specific relationship with the participant – the exception was in Family 1 because the two participants did not have other siblings. All participants reported sibling support in one form or another. All described their experience of instrumental support, which included organizational and financial support. Six out of 10 families specifically expressed experiencing emotional support from their siblings. On a Likert-scale (“1” = no support at all, to “10” = over and above support), participants' mean rating for experienced support by siblings was 8.03 (SD = 2.36; ranging from 3-10). On another 10-point scale that asked participants to rate their perceptions of closeness to siblings (“1” = distant and dissociated to “10” = very close and connected), siblings were rated at a mean of 7.66 (SD = 2.88, ranging from 0-10; one participant rated his sibling as “0”) in closeness. Furthermore, participants' described their perceptions of siblings' connections among each other in their families (see Appendix J). Participants from all five families expressed *good*, *excellent*, *great*, *strong*, *interconnected*, and *primary connections* with siblings. However, some participants also reported experiences of *bad*, *disconnected*, *zero respect*, and *less than* relationships between their siblings.

As for connections outside of the sibling system, participants identified the presence of extended family members and formal care from dementia care providers. Three of the families noted the presence of extended family support from spouses and/or their aunts and uncles, and two families indicated that friends, doctors, and formal care professionals had provided them with both emotional and instrumental support in the caregiving process.

Sibling Dyad Descriptions

Before moving to the results of the cross-family analysis of themes, it is important to understand the families that volunteered to be a part of this study. As noted above, five sibling dyads, consisting of four sister-brother and one brother-brother couplings, agreed to tell their stories. In addition to the gender breakdown of dyads, each family presented their own unique understanding of their situations and ways of approaching them – as will be described in the following results. To provide context for interpreting the results, below is a brief description of each of the five sibling dyads. In order to maintain confidentiality, participants' names were changed, as detailed in Chapter 3.

Family 1 – Zoey & Matthew

Zoey, 62 years old, and Matthew, 64 years old, made up the first sibling dyad that was interviewed. In their family of origin, there were only their parents and the two of them – no other siblings. Their father had died several years ago of cancer, and their mother, 88 years old, had recently been moved to an assisted living facility for health concerns related to dementia and Alzheimer's Disease. Prior to their mother moving into formal care, Zoey and Matthew had taken turns assisting their mother, who lived by

herself, with various tasks from picking up prescriptions to helping her operate kitchen appliances.

Both siblings had earned master's degrees and were still employed full-time. Zoey made her career as a therapist and Matthew as a consultant. Both were married about 20 years in duration, divorced around the same time, and had grown children with whom they felt close. Zoey was sweet, soft-spoken, a little introverted, but also a very engaging woman. As she told her story, she revealed a great depth of thinking about relationships with her parents and her brother. Matthew was a gregarious, lively, and very funny man – definitely on the extroverted end of the spectrum. As he told his story, he reflected depth and intention that was similar to his sister's narrative. Also, he had a light-heartedness about his experience, although he seemed equally as perceptive as Zoey.

Zoey and Matthew presented a unique situation in this study since they were the only siblings that were living together. As will be revealed in the results, their living together may attest to the strength of their sibling relationship in the dementia care process for their mom. Zoey had been based near her mother for many years, but Matthew had lived out-of-town for 30 years. However, he moved back to town a few years ago when his mother's health became an issue, and moved in with his sister. For our interviews, each chose to meet in their home, on separate weekends.

Family 2 – Jim & Bo

Jim, 66 years old, and Bo, 62 years old, made up the second sibling dyad that was interviewed. Their family of origin consisted of their parents, the two of them, and a third brother (Rbrother, 63 years old). Their mother had died several years ago, and their

father, 95 years old, had recently been moved to a supportive community where he had his own apartment and could come and go freely. Still, his apartment was attached to an assisted living facility and had a memory care unit to help with health concerns related to his cognitive decline and other illnesses. Because their father had been relatively independent, their part in his care was only just beginning.

Jim and Bo had received their advanced education degrees – Jim his Ph.D. in psychology, and Bo a Master's in education. As for their brother – Rbrother – Jim and Bo reported that he had decided to “stay put” (BO.22.12-22.14, Seaman, 2014c), indicating that Rbrother had not finished college. All three brothers in the family were employed still, but at varying hourly commitments (Jim part-time at 25 hours/week, Bo full-time at 40 hours/week, and they reported that Rbrother worked in his own shop – an extension of the family business – and they were not clear on the hours he put in). Jim made his career as a psychologist and Bo as a jeweler, videographer/filmmaker, and owner of real estate. Both were married and had grown children with whom they frequently connected. Rbrother, on the other hand, worked in the family jewelry business and had a child who was in high school. Jim was intellectual, diplomatic, and accepting of his role in the family and caring for his father. As he told his story, he was calm and even keel – one could get a sense that those characteristics would be developed in his profession as a psychologist, and be helpful in the caregiving process. Bo was openhearted and jovial – another very funny person. During the interview, he seemed to be an open-book. No question was off-limits, even when the answers revealed something unfavorable. He was

honest and accepting of himself and his family's situation, and he handled it with humor. There was much laughter during his interview.

One of the unique things about Jim and Bo's family was the balance of proximity to their father and each of the siblings' involvement in his care. Jim lived four hours north of their father and was only able to make face-to-face visits every other month. Bo lived part-time eight hours away on the Northeast shores of the Atlantic, and part-time one hour away in a small town just over the state border. On the other hand, Rbrother lived just a few miles away in the same town as their father. As will be shown in the discussion of results, closeness in physical distance actually seemed to be connected to less caregiving involvement, in Family 2 at least.

Family 3 – Erika & Patrick

Erika, 64 years old, and Patrick, 56 years old, made up the third sibling dyad that was interviewed. Their family of origin consisted of their parents, the two of them, and two other brothers (Gbrother, 68 years old, and Kbrother, 60 years old). Their father had died 25 years ago, and their mother, 90 years old, had been moved a year ago to a nursing home facility to help with her dementia, Alzheimer's Disease, and other illnesses. Prior to their mother moving into formal care, Erika had taken on the primary responsibilities for her mother's health, livelihood, and comfort, while her brothers alternated Saturdays caring for mom because they saw that "[Erika] needed a break" (PATRICK.34.26, Seaman, 2014f). All siblings lived locally and were within 45 miles of their mother.

Erika and Patrick were college graduates, as were their two other brothers. However, Erika was the only one of her sibling group who was still employed, working

32 hours/week. Her three brothers were retired. Erika made her career in landscape architecture, but Patrick, now retired, had been employed in law enforcement for 25 years. Their two other brothers, also now retired, had worked in professional roles: Gbrother as an engineer, and Kbrother as a park manager. Both Erika and Patrick were married and had their respective families, as did their brothers. Additionally, they had grown children with whom they were close – Erika’s children all living in town, and Patrick’s daughter in the military. Their brothers did not have children. Erika was warm, welcoming, and had a wealth of information. Indeed, her interview was the longest at two hours and 58 minutes. As she told her story, she revealed an expansive scope of the caregiving process for a parent with dementia, as well as personal triumphs and tribulations in navigating through waters of sibling conflict and insufficient information about family dementia care. Yet, she was engaging and genuine – she showed openness and hospitality during the interview – even offered homemade coffee cake. Patrick, also was welcoming and gracious, but with a bit of an edge. As he told his story, there was an intensity and unrest in the situations and experiences he revealed.

What stood out in Family 3 was the presence of unresolved sibling conflict. As will be shown in the results to come, Erika and Patrick shared distinct points of view on what they expected from their siblings in the dementia care process. In addition, the way their viewpoints were communicated also seemed to be connected to how the siblings were involved in relationships with each other and with the care of their mother.

Family 4 – Stevie & Mac

Stevie, 47 years old, and Mac, 48 years old, made up the fourth sibling dyad that was interviewed. In their family of origin, there were their parents, the two of them, and five other sisters and brothers (Vbrother, 49 years old; Msister, 45 years old; Gbrother, 43 years old; Rsister, 41 years old; and Lsister, 39 years old). Their father died several years ago, and their mother, aged 75, had been living between the homes of her children. Since the death of their father, their mother lived half of the year with one set of siblings in Manila, Philippines, and the other half of the year with her sets of children on both eastern and western sides of North America. Within the past year and a half, their mother had been showing symptoms of dementia (i.e., forgetfulness, repeating herself, misplacing important things, and general personality changes). Prior to the dementia symptoms, the siblings provided equal amounts of financial, logistical, and filial support to their mom. However, in the recent past they have been in the process of learning about what their mother has been experiencing and planning the next steps in maintaining her cognitive and physical health.

Stevie and Mac had received their master's degrees and were still employed. Stevie made her career as a Life Coach in addition to duties of stay-at-home parenting for her two children. Mac was working as a manager in auto repair. Both were married and had children in grade school. Their siblings also were educated – all went to college – and maintained professional roles in their careers. Stevie was outgoing, spirited, curious, and engaging. As she told her story, one could see her passion to understand what her mother was experiencing. Mac was easygoing, expressive, and accepting of his mother's

condition. As he told his story, he displayed inspiring warmth of his mother's experience, as well as empathy for his siblings' processes in understanding and accepting their mother's cognitive decline and related concerns.

An outstanding feature of Family 4 was how their cultural values connected with their filial expectations of caring for their mother. Both Stevie and Mac noted the expectation of eldercare that had been handed down not only in their family, but also in their Filipino culture. Therefore, part of the expectation was for their mother to live with her children. Complicating that expectation, however, was the fact that her children were widely dispersed. Thus, caregiving for their mother had to be balanced across time zones and across cultures.

Family 5 – Sharon & Kevin

Sharon, 54 years old, and Kevin, 44 years old, made up the fifth sibling dyad that was interviewed. In their family of origin, there were their parents, the two of them, and eight other sisters and brothers (Esister, 59 years old; Cbrother, 58 years old; Mbrother, 56 years old; Jbrother, 53 years old; Asister, 50 years old; Lsister, 48 years old; Dbrother, 45 years old; and Jsister, 42 years old). Both parents were still living – their father, 81 years old, had moved to a nursing home one year ago to receive more specialized care for his dementia and Alzheimer's Disease, as well as a number of other health concerns. However, their mother, 82 years old, had been living independently in the family home, and had taken an active caregiving role to her husband. Thus, as part of the caregiving process, Sharon and Kevin's roles had been indirectly supportive to their father primarily by helping their mother with caregiving planning and social support needs; both,

however, had regularly visited and spent time with their father in the nursing home. As for their siblings, involvement in caregiving had varied depending on many factors that will be discussed below.

Both Sharon and Kevin were college graduates, as were their siblings. Sharon was employed full-time, but just experienced a reduction in work hours to 20 hours/week. She made her career as a buyer for retail shops. Kevin was employed full-time and made his career in financial management, research and development for a large corporation. Sharon was never married and did not have children. Kevin was married and divorced and had a child in high school. As will be shown, their eight siblings had diverse lives that led them across states and out of the country - although seven of the 10 siblings still resided locally. Sharon was open, engaging, warm, and very easy to talk with – it was no surprise in her story when she mentioned her mediator role while she was growing up (SHARON.70.16, Seaman, 2014j). As she told her story, one gained a sense of how the mediator role may have developed in the complicated networks of her 12-person family of origin. Kevin was also engaging and diplomatic in his judgments of the various points of view of his siblings on their caregiving contributions and general roles growing up. As he told his story, he spoke of his acceptance of his siblings' choices of their involvement in the family, and he reflected on the differences in upbringing that may have accounted for their choices (KEVIN.35.10-35.12, Seaman, 2014i).

An important piece of Family 5's collective story was the significance of how generational choices and views of their parents shaped the atmosphere of the family among the 10 children. Sharon and Kevin discussed the strain between their parents that

led to strains in relationships among the children and feelings of disconnect (KEVIN.27.26; SHARON.57.11-57.13). In addition, having 10 children over the course of 17 years presented different challenges and opportunities for connection within the family (KEVIN.12.20-12.23; SHARON.60.1-60.27). Thus, as will be shown in the following results, in Sharon and Kevin's 12-person family, the passage of time and the structure of their parents' relationship seemed to uniquely influence the atmosphere of their family connection and caregiving contributions.

Cross-Family Interview Themes

From the cross-analysis of the five families, four superordinate clusters and 18 superordinate themes emerged in all 10 participants' narratives (see Table 2). Themes were selected based on their frequency in participants' stories, as well as the richness and depth they added in understanding the phenomena that emerged (Smith & Osborn, 2007). The four superordinate clusters included: 1) Individual Caregiver (Internal) themes, 2) Individual Care Recipient (Parent with Dementia - Internal) themes, 3) Relationships that Carry Individuals (External) themes, and 4) Cultural Guides (External) themes. Under each superordinate cluster, two to seven superordinate themes surfaced. Superordinate clusters and their accompanying superordinate themes have been summarized in Appendix K. Additionally, they will be considered in detail below, and each respective superordinate theme will be illuminated as the findings are discussed.

Table 2

Cross-Family Themes

Themes
Individual Caregiver (Internal) (Microsystem)
1 Caregiving and Sibling Personality Differences
2 Active Full Lives/Doings in the World
3 Competing Obligations
4 Burden versus Fairness
5 Sibling Closeness/Unique Bond and Alliance (Mesosystem)
6 Initiative Taking and Decision Making – Stepping Up (Mesosystem)
7 Use of Professional Role/Education in Caregiving Approach (Mesosystem)
Individual Care Recipient (Parent with Dementia – Internal) (Microsystem – Exosystem)
8 Life Events as Catalyst for Dementia in Parent
9 Parent’s Lack of Niche/Identity in Family System
10 Role Reversal
11 Formal Care as a Resource or Another Problem
Relationships that Carry Individuals (External) (Microsystem – Exosystem)
12 Roles Through the Years
13 Third Generation Connection (grandchildren involvement)
14 Contract Between the Generations/Intergenerational Themes
15 Support in Sibling System
16 Wide Reaching Support Network
Cultural Guides (External) (Macrosystem/Chronosystem)
17 Religion and Ethnicity as Guide to Culture
18 Different Time (Generational) – Relationship with Parents

Note. Cross-Family Themes were demonstrated in the interviews of all 10 participants of this study.

Individual Caregiver (Internal) Themes

The superordinate cluster of Individual Caregiver (Internal) generally represented participants’ judgments about individual sibling caregivers’ (including themselves) characters and their approaches to dementia care for their parents (see Table 2).

Participants judged their siblings and themselves in seven general ways: 1) caregiving

and sibling personality differences, 2) active/full lives and various “doings” in the world (JIM.3.3, Seaman, 2014d), 3) competing obligations in the caregiving process, 4) burden versus fairness in distribution of caregiving duties and roles; 5) experience of sibling closeness and unique bonds or alliances, 6) initiative taking – “stepping up” (PATRICK.3.7, Seaman, 2014f), and 7) siblings’ use of their professional roles/education in individual caregiving approaches.

Caregiving and sibling personality differences. The superordinate theme, Caregiving and Sibling Personality Differences, emerged as one of the most frequently discussed themes under the Individual Caregiver (Internal) superordinate cluster (see Appendix K). Participants talked about different caregiving responsibilities that they and their siblings fulfilled, as well as individual ways of being that impacted their approaches. For example, in Family 4, Stevie and Mac described differences in personality in their siblings and themselves, and how those differences impacted their approaches to dementia care for their mom. Stevie disclosed, “Our personalities among siblings are still there. I know I’m a Leo; I’m strong; I want my opinion heard. My brother Gbrother, the younger one, is also strong, but we don’t butt heads” (STEVIE.18.7-18.10, Seaman, 2014h). Additionally, she said of herself, “I notice I am being more and more impatient with [mom]” (STEVIE.43.21-43.22). In comparison to her brother, Stevie also noted, “For now in our last Skype, two of us were still hanging on to ‘no she can fight this’. Mac was more like ‘lets just not stress her out – just let her be.’ ...Mac is more of like laid back, lackadaisical, “let’s not hurt her”” (STEVIE.13.18-13.29). Mac corroborated Stevie’s perspective in his reflection that “I know my mom likes it nice and calm so she

only spends a week at the most with me. For the most part, when she is here she stays with my sister... My sister has a bigger house – it's like a mansion... but she's more of a professional. She likes it done" (MAC.23.12-23.17, Seaman, 2014g). Both Stevie and Mac noted differences in their personalities and thus differences in their approaches to caring for their mom. Interestingly, each of their personality styles seemed to be the reciprocal of the other; for example, in contrast to Stevie's strong and opinionated approach, Mac liked it nice and calm, laid back. Other sibling dyads in the study reported a comparable dynamic or having reciprocal complementary personality features and approaches to caregiving.

Similarly, in Family 1, Zoey and Matthew discussed their personality differences growing up and how they were represented in their caregiving to their mother. Zoey discussed how she had always taken a more emotional approach in her perception of things. She disclosed, "Oh, I have always experienced things on a more emotional level than he has. He has always struggled to understand what the big deal was" (ZOEY.30.14-30.15, Seaman, 2014b). In the previous statement, she noted the differences between the way Matthew and she have always perceived things. However, she discussed how differences in personality had impacted the ways they responded to caregiving for their mom. Zoey illustrated the difference: "When she first moved into the facility, it was awful because her anger was so unrelieved and it really shook me. Now he said, "if she's angry she's angry. This is where she needs to be." But when somebody is begging you to take her home..." (ZOEY.31.7-31.9). Matthew provided insight into the previous

statement, observing that the differences may have in some ways related to the relationship between Zoey and their mom. Matthew reflected:

... [Zoey] never came to terms with it. And ironically, and I've said this to her – the irony is – and she had a terrible time with our mom's dementia – much worse than I did. I was just much more philosophical about it, and sorry to see it, and it's sad, and discouraging, and so on and so on, and I wish it weren't happening to my mom. But ironically what it meant to my sister, I believe, is that now she was never going to be able to get our mom to love her. (MATTHEW.28.25-28.31, Seaman, 2014a)

Matthew also clarified, “but I tend to be more objective about it is what I'd say. I intellectualize it more than she does. I deal with it more on a more rational basis and she gets so wrought up about it” (MATTHEW.13.27-13.29). Thus, Zoey's personality characteristics to be more connected emotionally, and Matthew's personality to be more objective and philosophical, impacted how they responded to caregiving for their mother with dementia. Although Zoey and Matthew may have their differences in approaching caregiving, they both seemed to communicate openly with each other. Zoey expressed, “And I said to him, “we are different people. We are experiencing this in a different way. Your way is not better than mine, and my way is not better than yours.” They are what they are” (ZOEY.38.2-38.4). Zoey and Matthew acknowledged their differences, which also appeared as complementary personality styles and approaches to the caregiving experience. On one hand, Zoey was the “emotional” type, and on the other hand, Matthew was the “objective” type. However, in their stories, they not only recognized their unique ways, but also understood and accepted their differences.

Active full lives/doings in the world. One of the interview questions for this study was “what kind of things do you do on a daily basis?” It was a warm-up question intended to open discussion and help participants acclimate to the interview protocol. Unexpectedly, however, it revealed a backdrop for understanding siblings’ caregiving approaches and experiences. Almost all participants discussed their rich and “full life” (MATTHEW.2.11, Seaman, 2014a). In particular, Family 2, Jim and Bo talked about the various things they were “doing in the world.” Jim asked rhetorically, “What I’m doing in the world” (JIM.3.3, Seaman, 2014c), then went on to say, “And I have a lot of active things that I have always done that it’s really simply a rebalancing of how much I do of what... I’m a geriatric psychologist” (JIM.4.15). He, then described the various things he did outside his day job, “and then I also play a lot of music so... umm, I work with a number of groups and umm... Umm, I have no trouble keeping myself occupied” (JIM.5.13-5.15). Jim discussed his various musical groups and ventures. In addition to the number of bands he played in, he also discussed studio production of young bands CD’s, playing small parties, and collaborating with groups in playing different instruments. He said when he was not working or spending time with his wife, he was playing music (JIM.5.13-5.15). And when asked how his father’s care fit into all the creativity, Jim said, “And when I’m not doing that I’m really sort of taking care of my dad” (JIM.9.8).

Jim’s brother, Bo, also expressed involvement in a number of things, and in particular how it was hard to wear so many hats. Being involved with a number of

enterprises related to his family's jewelry business and his new interests in real estate seemed to keep him busy. He discussed the back and forth between his projects:

I either go to the office and do some work on the computer and deal with that downtown umm or I will work with various trades people to push my... our projects forward... yeah I've been involved in the jewelry business, I was involved in the watch business so I grew up in the retail business. Umm... I'm a gemologist...I came [to the Midwest from the East coast] because of my wife wanted to get back here to be close to her parents and I'm like, "yeah that's okay" because my dad is only an hour away and I can see him too and you know he's 96 so that would be a good thing and I've always been interested in property umm... (BO.3.1-3.27, Seaman, 2014d)

In addition, Bo talked in-depth about his video production business that stemmed from his passion and education in filmmaking. He finished his discussion of his active life by noting his difficulty with going back and forth between projects:

Right so I'm and it's tough because I'm pretty focused one way and I, it's like okay I'm doing this now, the house thing, and I'll do the video thing when I'm there and it's hard to have both hats on. (BO.6.8-6.10)

In Jim's and Bo's stories, they discussed many activities that they balanced – pursuits that were outside of the scope of caregiving. When asked how his father fit into his interests, above, Jim noted that when he was not doing all the things he did, he was caring for his father (JIM.9.8, Seaman, 2014c). When Bo was asked how he believed his father fit in, he responded that he was very grateful to have expanded his ventures from the East coast back to the Midwest, as it brought him closer to his father. He expressed:

My dad fits into it because he's my father and... there is no denying that. So how he fits into it is that I can for him - I love him very much, he is a sweet man, and given the opportunity to be here like I mentioned it was a no-brainer. It's like this

is awesome. I can, rather than seeing him twice a year or three times a year whenever I could make it out here from [the East coast] from before now, I have a foothold here I can see him, if I want to go see him, if I miss him or something I can jump in my car and it's just really nice for me. (BO.10.18-10.23; BO.11.1-11.5)

Jim and Bo seemed to say that although they led very active lives, that it was a “no-brainer” and that the care of their father was naturally a part of their schedule of undertakings. Their contribution to the caregiving seemed to be an extension of their “doing in the world.” This phenomenon of active full lives emerged in each sibling dyad’s collective story. Participants not only had responsibilities of caring for their parents, but also they had a myriad of projects pulling them in various directions.

Competing obligations. In some cases, participants saw various activities that siblings took on as things that were taking families away from their commitments to dementia caregiving for parents. These commitments or obligations were outside the immediate caregiving system and consisted of situations such as having gotten married, caring for children, caring for in-laws, and strained relationships with other family members. They were obligations that did not allow for ease in connecting with siblings and parents in the dementia care process. In Family 4, Stevie and Mac discussed competing obligations that related to their personal challenges in contributing to caregiving and what they witnessed from their other siblings. Stevie discussed the number of daily tasks that she completed in addition to dementia care for her mom:

Well first of all I have two young children, 11 and 9 and basically get up really early, get them ready, prepare their lunch, drive them to school. As soon as they are in school, I have a private practice, a life coaching practice...It's very hard and you know I know we are talking about my mom eventually, but when my

mom comes it gets even harder because now I am juggling, serving three different entities like my kids, and my mom is a guest, and my work. It is hard to insert my work in there so. (STEVIE.1.15-1.29, Seaman, 2014h)

Stevie pointed out difficulties when life events become duties to be juggled in a topsy-turvy balancing act of taking care of her children, caregiving for her mom, and inserting her work into the mix. However, according to Stevie, in her mom's system of care siblings contributed equally (STEVIE.33.15). Her brother Mac confirmed the equal sharing of duties (MAC.40.8, Seaman, 2014g), but had a perspective that possibly siblings' spouses had their own agendas that impacted the caregiving process. Mac reflected:

I called it - I said you know what - because the husband wanted to use the guesthouse for his friends too. That is where my mom was living. She got really comfortable there. So I am talking to my siblings - we are having this meeting, which is also through Skype. I said 'you know what I - like don't get me wrong' Rsister was not involved in this conversation. I mean I went to school with the guy so I like the guy but I think he is just tolerating mom at this point - he wants to have his life (MAC.46.27-46.29; MAC.47.1-47.3)

Above, Mac exemplified the strife in other sibling dyads' stories of competing obligations. In all five sibling dyads, participants talked about the presence of incongruous agendas of either a former spouse or another sibling's spouse who was "pushing things" in caregiving (SHARON.40.1-40.7, Seaman, 2014j), who was jealous of the sibling relationship (ZOEY.20.14, Seaman, 2014b), or who was caregiving for an in-law simultaneously to caregiving for own parents (ERIKA.18.7-18.9, Seaman, 2014e; PATRICK.13.5-13.17, Seaman, 2014f). These competing obligations impacted

participants' judgments of their own experiences in dementia care of their parent, as well as their siblings' involvements.

Burden versus fairness. Related to competing obligations, but distinct as its own theme, storylines of what siblings found burdensome and fair emerged from participants' data. This theme was exemplified by participants' personal feelings or witnessing their siblings' experience of missed opportunities, overwhelming stress, and unfair structures set up in the caregiving system. Within the stories of the five sibling dyads, participants talked about two types of burdens and efforts to create balanced and fair caregiving roles: 1) burden of parent's condition, and 2) burden of imbalance in caregiving between siblings. This dichotomy of burden was illustrated in the experiences of Erika and Patrick in Family 3. Patrick discussed burden related to his mother's condition. For him, the quirks of his mother's dementia combined with her other health conditions made things difficult. Specifically, Patrick talked about the irritation he experienced related to his mother's hearing loss and her subsequent paranoia and restlessness related to her dementia. He expressed, "I can't imagine having her, as much you know we love our mother but it gets very aggravating. It's the hearing problem you know" (PATRICK.31.2-31.3, Seaman, 2014f). Furthermore, Patrick asserted, "Its aggravating, love my mom to death but when it is 'what? What? What?' you know complaining about you know umm... you know it is aggravating to have a person with dementia living with them" (PATRICK.44.23-44.25). In these statements, Patrick epitomized the irritation that many participants expressed. In this way, participants felt burdened by visible changes, sometimes dramatic, in their parents' behaviors.

Also, Erika's story reflected the burden of her condition. She had cared for her mother in her home for three years, up until moving her mother moving to a nursing home a year ago. Erika described her daily dementia caregiving responsibilities, "So while she lived here, um, I *did* work. And I would have to get her up in the morning. Check her blood. Do the breakfast. Empty the commode. Get her dressed. Um feed her" (ERIKA.1.36, ERIKA.2.1, Seaman, 2014e). In this statement, Erika articulated the struggle to balance the care of her mother and working, which can be enough of a burden. Added to this, however, was Erika's mother's lack of acceptance of Erika's husband. She discussed her mother's insults:

Um one of the things that came out from my mother's dementia is they lose their tact or their diplomacy. They say whatever's on their mind... She made a comment about [my husband] and I said "mom, why are you still hanging on to that?" ... She had never forgotten that one of the Christmases when we were just married, he bought me a rocking chair. She thought that was horrible. (ERIKA.41.15-41.34)

Furthermore, Erika disclosed her hurt and confusion at why her mother would say such things when she and her husband had always treated her with love and respect:

And so when this conversation came up, I ended up crying to her... And I said "mom," I said "don't ... don't you see how well he treats me?... Um what .. what do you still have against him?" And she ... she'd give another example of ... "and I just I can't believe that you still feel this way." I said "he treats me better than dad treated you." (ERIKA.42.1-42.9)

Erika talked about her difficulty caring for her mom due to a number of responsibilities she had. In addition, what seemed to make things more burdensome was the lack of tact and diplomacy her mom had in voicing her opinions. For Erika, a long history of being

unaccepted had persisted and was now exacerbated by the dementia condition. Thus, though the burden of caregiving presented challenges of time and effort, the unfair way that Erika was treated by her mom was almost too much.

Other sibling dyads referred to the burden felt over how they were treated by their parents with dementia. For example, in Family 1, Zoey and Matthew also took turns being on the receiving end of their mother's insults. Like Erika, they each found their own ways to let go. Matthew told of how his mother would insult him to his face in public places. When asked his response, he said, "Mostly, I let it roll off my back. Water off a dove's back. For the most part" (MATTHEW.20.20, Seaman, 2014a). Zoey's response was similar to her brothers with regard to her mother's cruel comments. Zoey reflected:

It has become – I can comfort her now. And I want to because she is a lost soul. And if there is anything I can do to make her less lost for this period of time, I will. But I thank god that I only have to do it once a week. I've made my peace with it. (ZOEY.34.30-34.32, Seaman, 2014b)

In Zoey's and Matthew's responses, they seemed to have developed greater insight into their mom's condition, such that they were able to differentiate their feelings from their mother's condition, feel compassion for what their mother was going through, and be able to make peace with the situation. Therefore, even with the burden of insults, they were able to make peace and/or justify their mom's behavior and treatment toward them as related to her own condition.

In the stories conveyed by Family 1 and Family 3, participants discussed the weight they carried in dealing with their parents' behavioral changes related to dementia

onset. They also noted the fairness they found in the process from making peace and letting things “roll off their backs.” Yet, a second kind of burden that emerged was burden of imbalance in caregiving between siblings. This type of burden occurred in situations where participants wished to relieve their siblings of carrying all the responsibility of dementia care. Additionally, it was represented in participants’ evaluations of their siblings’ contributions to the caregiving process – or lack thereof. In Family 5, Sharon and Kevin succinctly shared their experiences of imbalance in caregiving. Sharon described how caregiving had become a sort of burden in that it grounded her in her hometown and made her reluctant to take a job out of state. She said, “It’s hard. Really strong pull. Close with most of my siblings really. And to pick up and leave, I should have done that when I was in my 20s” (SHARON.20.18-20.19, Seaman, 2014j). Furthermore, Sharon clarified, “Even though [caregiving for dad] is a big deal to me and I see it as paramount, I...I was unemployed three years ago, and I could have taken this job out-of-state and I didn’t, because this thing was looming” (SHARON.53.15-53.17). She discussed how her commitment to the caregiving process had taken priority in her life, and it was telling in how some of the commitment had become burdensome in that she felt it was hard to leave because of the “really strong pull,” as well as the “looming” quality of caregiving duty.

Sharon’s brother, Kevin, added clarification to Sharon’s expression of the looming quality of caregiving for their father. In his words, he referred to the “enormity of the situation” and needing to prepare for it. However, he provided empathy for his

sister's position and validation for her feelings related to the looming pull of caregiving.

Kevin disclosed:

If you're going to talk to your parents and one's in a nursing home and the other one is trying to piece it all together, you have to have a certain level of energy to be able to handle it... Because the last thing you want when you go out there is to go out there and be overwhelmed with the enormity of the situation. And, you come away leaving there depressed and sad and, mom is not really feeling good about it and dad doesn't know one way or the other. (KEVIN.14.17-14.24, Seaman, 2014i)

Furthermore, Kevin added, "You come away drained. You're drained" (KEVIN.15.1).

Also, he said, "[Sharon] gets wiped out too... And then she feels like why isn't anybody else stepping up like her" (KEVIN.29.22-29.25). In the above statement, Kevin expressed compassion for his sister's experience, but also he recognized the burden of imbalance in caregiving between his siblings. In each of their stories, the lack of fairness because of sacrifices of time and opportunities represented burden that Sharon and Kevin exemplified, especially in comparison to their other siblings' reluctance to step up. And so the personal sacrifices that they made over and beyond what their siblings did caused burden of imbalance in caregiving.

Family 3 also expressed burden of imbalance in caregiving. Erika discussed the intervention that her daughters had with her about giving up duties as the routine and regular caregiver of their grandmother, as well as their recommendation for their grandmother to move into a formal care facility. For Erika, having had her daughters' insight into the situation gave her the courage to connect with her brothers and pass on the burden (ERIKA.46.26-46.29, Seaman, 2014e). Erika stated:

My initial feeling after this meeting with the girls was, I can't do this. But when I came home that night, I wrote an email to my three brothers. And I said, "today my three daughters lovingly told me that grandma cannot live here anymore. And so I want the three of you to figure it out. And just let me know what you come up with..." And I'm like "okay – I've done this for three years now. You guys are gonna do this. I'm not running around." (ERIKA.46.18-46.29)

In the above statement, the burden of the imbalance of caregiving seemed to have taken its toll. Erika exemplified the imbalance in her disclosure that she had done the majority of caregiving duties for her mother and it was time for her brothers to take on the burden. Therefore like the experiences of Sharon and Kevin in Family 5, Erika also felt the lack of fairness in the personal sacrifices she made in caregiving, which were over and beyond what her siblings contributed.

Erika's brother, Patrick, corroborated the burden in imbalance of caregiving. He reflected on when things seemed to reach a critical point and the caregiving roles needed to shift. He expressed, "but Erika goes, "this is becoming very burdensome for us, and if things don't change," something like "you know, I'll drop her off at your house for three months and you will have her"" (PATRICK.5.10-5.13, Seaman, 2014f). He illustrated the tension caused by the imbalance in caregiving due to his sister's in-home care of their mother and the brothers' seemingly minimal contribution to the dementia caregiving process. Again, the burden that he recognized his sister was experiencing was due to imbalance in caregiving between siblings.

Burden of imbalance in caregiving was expressed in all participants' stories. Some had insight about the imbalances in care, while others became aware only when ultimatums were made. Additionally, participants felt burdened by the changes in their

parents' ways of being related to their overall conditions. Behavior changes, lack of tact in expression, and harshness in treatment by parents were discussed as points of strain in the dementia caregiving process. However, some participants seemed to feel fairness in caregiving as exemplified in their making peace in relationships with their parents, and in their siblings' recognition of how participants were helping their parents. Interestingly, siblings that were most empathic toward their siblings' burden were the pairs from this study (and reportedly not their siblings who were not a part of the study). Thus, participants seemed to self-select siblings to which they were most compatible. In these dyads, siblings seemed to be mutually connected, understanding of one another, and facilitative in their sibling's general lives and caregiving roles. They seemed to have already established some sort of bond or closeness.

Sibling closeness/unique bond and alliance. Participants told stories of their connections with their siblings. In all stories there emerged consistent accounts of sibling closeness. This was represented as hanging out (BO.75.6-75.20, Seaman, 2014c), talking with (SHARON.25.4-25.22, Seaman, 2014j), traveling to see each other (MAC.27.3-27.10, Seaman, 2014g), enjoying the company of (BO.34.7-34.8), feeling trust and validation (MATTHEW.19.6-19.9, Seaman, 2014a; ZOEY.8.21-8.25, Seaman, 2014b), contributing to the livelihood of (MAC.54.5-54.14), and seeing the sibling group as a sort of team (STEVIE.19.4-19.14, Seaman, 2014h). It was also represented in specific alliances forming between pairs of siblings in the family (JIM.12.9-12.22, Seaman, 2014d; ERIKA.27.26-27.31, Seaman, 2014e). In these alliances, two siblings would form a close connection seemingly at the expense of a close bonding with another sibling.

Family 5 illustrated storylines of sibling closeness. Sharon and Kevin talked about how good it was to have such a large sibling group to share their lives. Kevin disclosed, “I mean it’s good that we have lots of brothers and sisters, but it’s good... because we each try to do whatever we can” (KEVIN.14.3-14.4, Seaman, 2014i). Sharon added to Kevin’s affirmation of the goodness in having a large sibling group. She discussed how she and her siblings regularly visited and talked with one another (SHARON.23.21, SHARON.25.21-25.22, Seaman, 2014j), how they have helped each other with stuff (SHARON.27.19-27.22), and how they offered insight and really listened (SHARON.28.10, SHARON.33.16). Sharon talked about how the aforementioned qualities added to her perception of the siblings as a sort of team. She disclosed, “I thought that we would always be close, tight, like be us against the world” (SHARON.52.12-52.20). Sharon and Kevin’s perspectives represented the sibling camaraderie and caring that seemed to appear in all participants’ stories. Thus, sibling fellowship brought them emotionally closer together.

In Family 1, Matthew described how the camaraderie that he and his sister shared was important because it allowed for a safe place to converse in the way that some married siblings might do with their life partner. He explained:

We can hash things through. I listen to what she has to say and give it great weight. And she listens to what I have to say and gives it great weight, and we can come to a meeting of the minds to decide what the best thing to do is...(MATTHEW.19.6-19.9, Seaman, 2014a)... I mean we’ve had that conversation. And again, that’s a form of support between us. Like the kind of conversation that you might otherwise have with a spouse, but neither of us is married right now. So happily, we each have somebody close enough to us to have that conversation with, you know, and be listened to. (MATTHEW.25.3-25.6)

In Matthew's story, as well as in Sharon's and Kevin's stories, the importance of having sibling closeness and connection outside of caregiving tasks was exemplified. What emerged was a collective sense of the importance of siblings listening to, sharing information with, taking time for, and caring about each other. Indeed, this sibling closeness was so much a force in one of the families that friends would comment on their connection. Stevie, from Family 4, revealed:

Friends would always say "you're like one big group of friends" because, you know, similar ages. We can all go out together, party together; so where as some families with siblings don't really do that. We were really close; each one got married; we were always so sentimental about that. So the dynamics in our core family, the seven siblings was really very close like my maiden name is Tomas just like Mac's is so we used to call we still call ourselves the Tom-Team (STEVIE.19.4-19.14)

Stevie commented on the impact of their sibling bond not just on connecting siblings in one solid unit, but also the effects on how they were perceived by friends and their extended family members. In her story, she talked about how she noticed disconnect in her cousin's families and how her connection with her siblings was something that she and all her siblings wanted to uphold. She disclosed the importance of supporting the relationships between their children - "third generation" – which seemed to emphasize the importance of sibling closeness in keeping the family solid (STEVIE.20.2-20.15). Mac, Stevie's brother, also discussed the "Tom-Team" closeness of his family. He added, "I was going to say we were a very close family almost like an ideal family in the Philippines. Some called us - compared us to the *Sound of Music* family" (MAC.54.5-54.6, Seaman, 2014g). Both Stevie and Mac discussed the impact that their sibling

closeness had on those outside the family unit. Their stories highlighted the differences that sibling closeness can make on siblings' perceptions of themselves and how others might perceive them. Indeed siblings seemed to form alliances when they felt heard, cared for, and that someone was there for them.

Nevertheless, in some families the closeness formed with some siblings seemed to come at a cost to others. In Family 3, Erika and Patrick talked about how helping each other out in the dementia care for their mother helped them to grow closer, but that their brothers remained disconnected. In this way, an alliance was formed between the two of them, while their brothers disengaged. Erika remarked:

And then Patrick started to realize how much work it was. Much quicker than the other two ever caught on... And Patrick always said to me, you guys are saints. You are saints. And he would just say thank you for doing this. (ERIKA.18.31-18.35, Seaman, 2014e)

This statement provided an example of the alliance that began to form between Erika and Patrick. Interestingly, Erika was almost 10 years older than Patrick and had noted how they were as close as they could be growing up with the age difference (ERIKA.19.14-19.15), but as they were caregiving for their mom they became even closer. However, this closeness came at a cost to at least one of their brothers. Erika explained:

KBrother just had the wrong perception of this. The wrong perception...which started way back. And I think the straw that broke the camel's back is when Patrick had to play the reasonable one in the family even over his oldest, oldest brother. And say, you have to do more here and it was not. I mean I don't think either of them took it well but KBrother took it really bad. (ERIKA.26.10-26.15)

Erika disclosed the tension between her brothers once Patrick confronted them about their lack of contributions to dementia care for their mother. Yet, as can be seen in the statement above, she seemed to maintain the alliance with Patrick by possibly downplaying Kbrother's response to Patrick's confrontation by saying he had "the wrong perception." Additionally, she may have supported separation between her brothers by indirectly affirming Patrick's confrontation as "playing the reasonable one in the family." In this way, she compared the behaviors of one sibling against the other, which may have created judgment of what was reasonable and what was unreasonable. And so the alliance between Erika and Patrick seemed to be upheld.

Patrick also discussed the bond that had formed with Erika compared with the discord he felt with his brothers. He told of times when Erika would connect with him and ask him to check in on their mother (PATRICK.2.12-2.19, Seaman, 2014f), and of times he would care for their mom on additional weekends during the month to give Erika a break (PATRICK.34.2-34.6). He talked about how Erika asked him to not respond to an email that she was going to send the brothers to request that one of them take mom while Erika was out of town. In this way, they formed a covert alliance to see which disengaged brother would step up to take over the dementia care of their mom (PATRICK.11.1-11.6). Patrick said, "Erika didn't want me [to take care of mom that weekend] because we took her for many weekends and she wanted those guys to figure it out" (PATRICK.10.15-10.18). This situation illustrated the recognition that Patrick felt from Erika's acknowledging of his support and assistance in caregiving, but also the possible perception of disengagement of the brothers. And having Erika's

acknowledgement seemed to be very important to Patrick's perception of his relationship with Erika. He revealed:

Erika took on more of the leadership role and making sure everything is taken care of and you know so me and Erika communicate with each other because she knew we were doing what we could. Trying to get the other siblings to help so she appreciated that. (PATRICK.49.26-49.29)

In the previous statement, Patrick noted the communication that Erika and he had made in their efforts to get the other brothers involved. Erika's and Patrick's connection in the sibling caregiving system demonstrated a form of sibling closeness that took shape as a sibling alliance – a relationship that supported the siblings who were engaged in helping each other, and seemed to come at the expense of isolation and rejection of siblings who were disengaged from the sibling alliance. Thus, beside the closeness of spending time together, listening to one another, and feeling of friendship that families 1, 4, and 5 expressed, participants also noted specific relationships that formed within the sibling system that were more indicative of alliances rather than sibling closeness.

Initiative taking and decision making – stepping up. As was shown in the discussion above, some siblings found it easier to bond and connect when their siblings were “stepping up” and taking initiative to help. This type of initiative taking was present in the stories of all participants. The act of stepping up was particularly characteristic of Family 3's caregiving experience. Patrick discussed his observation of initiative taking by his sister and stated “My sister stepped up to the plate more than anybody” (PATRICK.3.6-3.28, Seaman, 2014f). He went on to describe how his sister had taken on

the majority of dementia care responsibilities for their mom, but after observing the imbalance that he and his wife stepped up to the task. He added:

Now we stepped up to the plate more than my oldest brother and Kbrother. Yeah we started taking her on weekends because when this came to a head we saw that she needed help so we were the first ones to say, okay I'm going to pick her up on Friday night and bring her back Sunday. (PATRICK.5.18-5.22)

In Family 3, “stepping up” and taking initiative seemed to not only be a way of supporting their mother in her dementia care, but also as a way of supporting their fellow siblings. As exemplified in Patrick’s and Erika’s accounts, stepping up was crucial to maintaining harmony and balance in the caregiving system. In particular, Erika discussed how taking on the majority of dementia care had become too much to handle, which was observed by her sister-in-law. It was her sister-in-law who fostered Erika’s reaching out to her brothers to get them to “step up” to the caregiving tasks. She said:

...but she knew that the brothers, my brothers needed to step up... Yeah. She didn't like the fact that I was doing everything... And um so then we started this rotation system where every third week they would come and get her and I would write their names on the Saturday schedule and they would come in the morning. (ERIKA.18.9-18.13, Seaman, 2014e)

Having her brothers step up to assist with the dementia care for their mom helped her in that it gave her time on the weekends to do things that were important to her. However, Erika also seemed to benefit from her sister-in-law stepping up in that she called attention to the fact that Erika’s brothers had to contribute their part in the dementia care responsibilities. She later added:

And I'll tell you they...they rose to the occasion... Separately. But they did it... They all mobilized... and KBrother was actually the one that found Elmcroft because as I mentioned earlier a friend of theirs' mom was there... So he looked at that place. He looked at a couple of others. GBrother looked at a few. Patrick...They all did their homework. And they reported back to me and they would say "I think this place warrants a visit from, you know, somebody else." (ERIKA.47.3-47.15)

Stepping up as discussed above, therefore, was a way to balance the responsibility and help fellow siblings in the family. In Erika's account, although she had stepped up to take on the majority care for her mother, she benefited from her brothers making the decision to help her, as well as their mother. Still, by Patrick's account, he and his brothers benefited from Erika's stepping up. Patrick reflected, "God bless her for doing that you know. She did it in... I was never in that role where she lived with us ever" (PATRICK.3.26-3.28, Seaman, 2014f). Patrick seemed to ponder the weight of responsibility that his sister had taken on and show gratitude for her caregiving for their mother.

In contrast to the benefits of stepping up in dementia care, participants also discussed their disappointment when their siblings did not take initiative. In Family 5, Kevin talked about his nine brothers and sisters and their initiative taking in dementia care responsibilities. He disclosed:

And, that's where I'm counting on my older brothers and sisters to step up because they don't have a teenager. They're not a single parent. They're not on the other side of town. The ones who live closer... You know, you think there's a pecking order to the responsibility to take care of the parents. The older ones who have, maybe not the resources, but the time... More flexibility, you would think those would be the ones to step up... We're lucky that there's enough of us, um, it would be much more difficult if there was fewer brothers and sisters because then everybody would have to step up more. (KEVIN.29.9-29.18, Seaman, 2014i)

In Kevin's account, he revealed his expectations of how his siblings should step up in the dementia care for their father. In his perspective, some of his older siblings without children in the home should have taken on more caregiving tasks because of their assumed flexibility and time to provide care. Furthermore, he observed that even with ten sisters and brothers in the family, there was a disparity in caregiving, and those siblings who seemingly had more time and resources to give were not taking initiative as much as siblings without flexible schedules and resources. Thus, stepping up or initiative taking not only helped to foster more harmonious and balanced lives for caregiving siblings, as well as give relief, but the absence of siblings' decisions to play a part caused confusion and disappointment in participants' perceptions of filial responsibility. Yet, the entire dementia care process seemed to be confusing to a couple participants. Indeed, some noted the numerous questions that arose when trying to figure out the care plan for their parents (SHARON.31.3-31.21, Seaman, 2014j; ERIKA.73.24-73.26, Seaman, 2014e). Relying on themselves, participants revealed creative ways they used their unique talents and skills to find answers to dementia caregiving questions.

Use of professional role/education in caregiving approach. A pervasive theme in participants' stories was discussion of skills that they brought to the caregiving system through professional roles and education. In some cases, participants' and their siblings' careers have provided them with direct answers about questions related to health and caregiving issues of their parents (MATTHEW.33.26-33.29, Seaman, 2014a; ZOEY.26.13-26.18, Seaman, 2014b; JIM.4.14, Seaman, 2014d; SHARON.26.7-26.10, Seaman, 2014j). In other cases, participants discussed how their organizational and

financial planning skills contributed indirectly to dementia caregiving (BO.29.7-29.9, Seaman, 2014c; STEVIE.27.21-27.28, Seaman, 2014h; PATRICK.33.2-33.7, Seaman, 2014f; KEVIN.20.21-20.24, Seaman, 2014i). Yet, some participants believed their contributions were greatly informed by their self-motivated education and experience to help loved ones who were dealing with the challenges of dementia (MAC.4.4-4.7, Seaman, 2014g; ERIKA.43.14-43.23, Seaman, 2014e).

In Family 2, Jim discussed his career as a geriatric psychologist and how he saw many clients with forms of cognitive decline and dementia (JIM.4.14). He noted that being in a professional role where he treated clients with forms of dementia helped him to deal with his father's issues. He said, "well, see as a psychologist it's easier because I am always –professionally, I am always concerned about people's well-being" (JIM.65.12-65.13). Based on what Jim had been exposed to in his line of work, he discussed his interest in ensuring his father's physical safety, but also protection of his assets. He noted how he had seen other aging people be taken advantage of by mail scams, and as a result, had created a system where he and his brothers would go to their father's place to check in on him, but also help him sort important mail from the "junk" mail (JIM.30.3-30.5). For Jim, he had seen his clients fall victim to scams, and he did not want his father to go through a similar situation.

Some participants talked about how elements of their professional roles indirectly transferred to caregiving tasks. Particularly in Family 5, Sharon reported that one of her sister's was a nurse and that her knowledge about medication had become a very practical tool in helping the family caregivers understand the effects of the medication on their

father, as well as the targeted goal of each drug. She said, “Lsister, she’s a nurse, a trained nurse. So she’s very, well she was pretty involved with his medication issue... So she would go thru his meds and stuff so she’s involved” (SHARON.26.7-26.10, Seaman, 2014j). She went on to say, “She knows her drugs and affects of drugs and what I can find out about that, “I know someone I can ask about that for you.” So she knows the ins and outs” (SHARON.34.8-34.9). Sharon revealed that her sister took such a role in the management of their father’s medication that she helped their other siblings and their mother to ask important questions about drugs prescribed for their father, as well as providing advice on how they could help in the medication management.

Sharon’s brother, Kevin, also discussed how his and his brother’s work in the corporate finance world helped indirectly in the care of their father. He discussed how his knowledge of financial management and his brother’s technical and organizational skills as a computer programmer helped their mother in balancing and managing their financial accounts and assets, so that they could maintain their father’s lifestyle in the nursing home. He disclosed, “He and I have put our heads together, and, of the bunch of us he is, he’s had a corporate, he’s a computer programmer, he’s had a corporate job. He’s more successful than most anybody else. So, he has the resources and the time and the organizational skills to help my mom” (KEVIN.20.21-20.24). In his account, not only were he and his brother able to contribute to the caregiving with their unique talents, but they came together in the task and were able to support each other. Although their caregiving may have been indirectly beneficial to their father, they seemed to directly support one another.

Contrary to building off skills and aptitudes that participants and their siblings already had, some reported that they had to actively research and learn for themselves the strategies and skills needed in dementia caregiving. In Family 3, Erika's experience best exemplified the personal research she had to do – over and beyond the information she received from her mother's doctors – in helping her mother. She talked about reading materials that helped her understand what her mother was experiencing. Specifically she noted learning information that shed light on her mother's condition, “[mom] displayed Sundowners Syndrome... Which I didn't know anything about that.... But in fact from what I read Sundowners Syndrome is a behavior that shows itself before dementia or part of dementia development” (ERIKA.13.6-13.29, Seaman, 2014e). Erika further disclosed that Sundowners Syndrome showed characteristic behavior issues of dementia patients who showed hallucinating, becoming restless and irrational (ERIKA.13.16-13.17). Still, Erika discussed her frustration in the difficulty of accessing resources for dementia care. She disclosed, “And I didn't even know what kind of facilities were available for her at this stage because I don't know. Unless you do your homework way ahead of time, this situation falls in your lap and then you figure it out as you go” (ERIKA. 43.14-43.23). Furthermore, she added:

I guess it's kind of what I talked about most recently. And that is that I think people who find themselves in this situation with a parent, you know, don't know what help is available. And you know how to go about coping... You know and getting some relief. So, I don't know. It's just there's not bulletin boards out there that say “hey, call this number if you've got a parent that's losing it.” You know... Um, because not everybody, you know is curious enough to try to find it on their own because they don't know it exists. So I don't know how we help like the general population. And part of me thinks that maybe lower income people might have...I don't know, they might have more opportunities. I don't know. I

know that my mom didn't qualify, you know, for things... Because she had money in the bank. (ERIKA.73.22-73.34)

Erika shared a common concern among the participants: locating resources and information about dementia caregiving was a challenging task. In her experience (as well as other participants), there were no professionals directing her to information about dementia care. On her own initiative, she found out about characteristic features of dementia onset (i.e., Sundowner's Syndrome), as well as the possible care facilities that would admit her mother with her many health concerns. From her vantage point, educating herself on the numerous caregiving considerations was imperative. It served as one of the ways that participants and their siblings contributed to dementia care responsibilities.

However, use of professional role and/or education in caregiving was just one of the superordinate themes that fell under the Individual Caregiver (Internal) superordinate cluster. In this cluster, participants offered evaluations (both positive and negative) of their contributions and connections in the caregiving process, as well as that of their siblings. Yet, besides individual caregivers experience in the process, participants also disclosed their perceptions of their parents experiences in developing dementia and being cared for. In the next section, superordinate cluster, Individual Care Recipient (Parent with Dementia – Internal) will be explored and participants' viewpoints on their parents in the dementia experience will be discussed.

Individual Care Recipient (Parent with Dementia – Internal)

The superordinate cluster of Individual Care Recipient (Parent with Dementia – Internal) generally represented participants' perceptions of their parents' experiences in cognitive decline and dementia, and their subsequent treatment (see Table 2).

Additionally, this cluster represented participants' hypotheses about how and why their parents developed forms of dementia. In this superordinate cluster, there arose four main superordinate themes: 1) life events as catalyst for dementia in parent, 2) parent's lack of niche/identity in family system, 3) role reversal, and 4) the presence of formal care in the caregiving process as either a resource or another problem.

Life events as catalyst for dementia in parent. In almost all participants' stories, they discussed their parents' onset of dementia connected with certain triggering events. Participants did not seem to know what was unfolding while they were in the process of noticing their parents' decline. However, most of them talked about how in hindsight they saw things that they took for isolated events or related to some other condition as actual signs of dementia onset in parents.

Two families disclosed their speculation that their parents' dementia might have been related to already occurring illnesses. In Family 3, Erika and Patrick discussed how their mother's health issues related to diabetes seemed to be the catalyst for dementia onset. Erika reported that several years ago, her mother had been admitted to a hospital for low blood sugar. She went on to say that while her mother was in the hospital overnight, she became restless and ripped out all of her IV's. She said:

And in the morning I came, the nurse kind of stopped me in the hallway and said, “your mom ripped out all of her IV’s last night. She’s really upset.” I was literally trembling because I did not know what was going on. And I had thought it was something to do with her diabetes that she you know I said maybe she has low blood sugar... But in fact from what I read, Sundowners Syndrome is a behavior that shows itself before dementia or part of dementia development. (ERIKA.13.19-13.29, Seaman, 2014e)

Years later, after having cared for her mom through the complications related to her mom’s diabetes, Erika had read about “Sundowners Syndrome.” The actual condition known as Sundowning Syndrome occurs in the evening hours around individuals’ typical time to sleep (Bedrosian & Nelson, 2013). It shows itself behaviorally as agitation, aggression, restlessness, and general disruptive behaviors. Most often, individuals with dementia experience Sundowning Syndrome, although it also can present itself with non-dementia related illnesses (Bedrosian & Nelson, 2013). Looking back, to Erika it was clear that the restlessness that her mother experienced while in the hospital might have been a sign of dementia spurred on by her illness. She said, “So you know this kind of behavior started and it was probably precipitated by the you know the diabetic crisis” (ERIKA.14.17-14.18).

Patrick also believed that his mom’s dementia onset might have been precipitated by her steady decline in health. He disclosed, “We would take turns doing that and it just got steadily more problematic with her issues” (PATRICK.3.5, Seaman, 2014f). Helping mom help take care of herself, gradually, became tough because the severity of her health conditions worsened. Yet, Patrick also noticed that perhaps her lifestyle contributed to her decline. He disclosed, “Living by herself and it was a slow steady progress of you know somebody had to go over there and help clean and we took her shopping and doctor

appointments” (PATRICK.3.3). In Patrick’s point of view, not only was his mother’s diabetes a contributing factor, but also living by herself could have been a catalyst for her cognitive decline.

Sharon, from Family 5, also reported how the build up of health concerns seemed to relate to her father’s developing dementia. She noted, “So it was just, things just started building... ‘Cause he’s, got a lot of issues going on. He has diabetes. He has diverticulitis” (SHARON.12.1-12.21, Seaman, 2014j). In Sharon’s perspective, the gradual increase in complications related to her dad’s illnesses might have precipitated her dad’s dementia. Yet, similar to Patrick’s account in Family 3, Sharon and her other family members noticed lifestyle factors that might have been catalysts for the onset of dementia. She disclosed:

...then things just kind of progressed. And then, it must be two years ago, he took a bad fall in the living room while he was sitting on the computer chair... And my mom thought he had a stroke... Turns out, he didn’t...He was fine. Nothing was wrong. Went to the doctor. And all that stuff. But she really thought that’s when it all started... So she just started keeping more of an eye on him and as the months progressed he just kept getting more and more withdrawn. He stopped going to bed on time and started sleeping and sleeping and wandering all thru the house... (SHARON.9.4-10.6)

In Sharon’s account of her dad’s fall, there were no illnesses or disorders that could be linked – at least those that could be diagnosed by her father’s doctors. However, in her mother’s and her point of view, after the fall was when her dad began to withdraw more, sleep at unusual times, and wander about – things that were atypical to his lifestyle.

Most often, participants talked about catalysts that were related to isolated events, like the fall that Sharon’s dad took. In Family 2, Jim and Bo discussed several events,

which occurred relatively simultaneously, that seemed to be the catalysts for their father's cognitive decline. Both brothers noted that just before they began noticing their father's change their mother had passed away. In addition, they remembered the trauma that their dad had experienced with two hurricanes going through where he lived within nine months of his wife's death. Jim reported:

Umm, and then he, it was, there were a number of traumas at that time in addition to her death. Within 9 months I think there were two hurricanes that went basically right through, one literally through his condo... But I think that the friends and folks he sort of connected with down there just had not – they just sort of drifted away. I don't know how much of that was his behavior...we said you know, we got his stuff and are coming back to [the Midwest] because he was down there but he wasn't doing anything. It seemed like it was just depressing to me. (JIM.15.20-16.21, Seaman, 2014d)

To Jim, his father having experienced the death of his wife, and two hurricanes that displaced him from the home that he and his wife shared, seemed to be the catalyst for his father's cognitive decline. Jim's brother, Bo, also observed similar connections. In the aftermath of the traumas his father experienced, he noted how he and his brothers became involved in their father's care. He said:

Yeah right after, it was pretty obvious right after she left and umm now it is a different situation and he's 10 years older, he's 96 and his health is going down. So we're all involved to try and keep him in a good state of mind. (BO.14.4-14.6, Seaman, 2014c)

Bo also reported that he noticed his father's change in social connectedness after his mother's death and the experience of the hurricanes. He reported that after the hurricanes had destroyed his father's condo, his father was living with friends, but possibly

overstaying his visit. Bo believed that his father had disconnected from social cues that would indicate that it was time for him to find his own place (BO.13.20-13.24). It was at that point in time when Bo and his brothers noticed changes that would, in hindsight, indicate the beginning stages of dementia for their father.

Parent's lack of niche/identity in family system. As was indicated in the superordinate theme of Life Events as Catalyst for Dementia in Parent, some participants perceived that their parents' dementia was triggered by traumatic events that set them into withdrawal and disconnection from the family. However, another theme arose in which participants told stories of overall lack of niche or identity in the family system. Participants perceived that their parents' lack of niche or identity seemed to occur when their parents' independence was threatened by certain freedoms being taken (e.g., driving privileges and ability to hear), and when parents who were always dependent on someone found they did not have a primary source to depend on (such as a spouse).

In Family 1, Matthew discussed how devastated his mother was when he and his sister took their mother's car keys from her – an action that he equated to taking away the last stitch of his mother's freedom. He revealed:

She was still driving at that time... Yeah, it was kind of like “EwwwUghhh”, and finally we had to bite the bullet and take her car keys away. That was a big hurdle of course... [and she said], “You are not going to take my car keys away!” So it was the opposite of what the experience of turning sixteen is. Once you get your driver's license, then suddenly you've got wheels, you've got freedom, you can go where you want to go. But here's my mom, at 80 years old, and suddenly she LOST that freedom. Well, I wouldn't be too happy about that either. And she wasn't happy about it... (MATTHEW.10.1-10.16, Seaman, 2014a)

In Matthew's perspective, his mother's health problems had progressed to a point that taking away the car keys was a necessary action. He noted that doing so was a "big hurdle" and later on in his story he clarified why. He said, "And it's weird, and it's my mom. And as I have said, who was once a very competent, and independent, and functional person, and in her dotage, she is not!" (MATTHEW.14.5-14.7). He went on to add, "That this person has lost their identity" (MATTHEW.23.12). Thus, losing certain freedoms, such as being able to drive, impinged on his mother's independence. Yet, to his mother, independence was one way she was identified, and not being able to function as an independent being might have contributed to her lack of niche in her life.

Hearing loss in parents was another circumstance that seemed to impact participants' viewpoint of their parents' perceived identity in the family system. In Family 3, Erika discussed how her mom's hearing problem seemed to cause her mom to withdraw. She disclosed:

Because of the hearing problem. That in itself I have read that could cause people to withdraw because they're cut off from their world. And when you can't hear conversations in the room um and what she suspected is that we were always talking about her and she would say at dinner "I think I'll just go to my room." And I'd say "why mom?" And she'd say "I just don't like you talking about me." And I'd go "we're not talking about you, I'm talking about work." You know and so that withdrawal and that kind of paranoia thing. The little wall that went up that was dreadful. (ERIKA.2.12-2.23, Seaman, 2014e)

Erika noted how the difficulties that her mother had in hearing things, such as the television, had caused her mother to withdraw possibly because her mother felt cut-off from the world. Additionally, she noted that her mother seemed to become paranoid that others were talking about her, and that suspicion caused her mother to withdraw even

more. Yet, she went on to add that even the family had a hard time adjusting to her mother's changes. She said:

We would bring her out here with us in the evening to watch TV but a lot of people in their upper 80's have hearing problems as well. And so she would want the TV blasting... And we really couldn't have it and so we got her these TV earphones and she wouldn't wear them so. So it was hard to integrate her into our family life. (ERIKA.2.4-2.12)

Erika brought up not only the difficulty that her mother was having in dealing with the barriers to communicating because of her hearing problems, but also the troubles in integrating her mother into her family because of the apparent differences in ability to hear and connect. Possibly, the lack of freedom on top of no longer feeling ease in being part of her family television time (at the very least) also contributed to Erika's mother's withdraw and lack of niche in the family.

Another way participants perceived their parents' experience of lack of niche or identity in the family system was when their parent who had always depended on another (i.e., a spouse) no longer had a consistent source to rely upon. Stevie, from Family 4, exemplified this with her story her mother's dependency. She disclosed:

Some of us think that it might just be enabling her or spoiling her. She's this helpless individual really. She has always been this dependent type. So we feel like "no." My other brother is like, "no," we can really put our foot down and say "no mom you have to help yourself – you have this condition." During her lucid moments "why don't you rise above it." While she's lucid not when she gets into this whole spiraling down but when she is aware let her take ownership of the condition and help her help us. (STEVIE.14.2-14.8, Seaman, 2014h)

In Stevie's account, her mother's dependency had led to a pattern within the family to not let her take responsibility. Yet, in her story she reported that at least part of her sibling group agreed that at least when their mom was in a lucid state of mind, that they could teach their mom to take care of herself. Stevie clarified her desire to foster her mom's ownership of her condition and revealed:

Because once they start feeling helpless, granted she is not the independent person, but there is still some, you know some sense of "I can make decisions for myself" and once you rob her of that then she will just feel like a vegetable. (STEVIE.26.19-26.21)

Thus, whether her mom was a dependent type or not, taking away any freedom, in Stevie's point of view, would take away any type of will to act, and leave her mom feeling incapable of normal physical or mental activity.

Stevie's brother, Mac, elucidated on their mother's lack of taking responsibility in her health concerns. Mac discussed how added to his mother's dependent style, she also spent much of her time traveling to see her kids. He explained, "She has seven children so she visits us. She has a couple here [in the Midwest], that's me and Stevie. Sister in LA, a brother in Canada... And then the remaining siblings are still in the Philippines" (MAC.2.17-2.20, Seaman, 2014g). Mac added that his mom not only visited, but had to assimilate to U.S. culture that was very different from her culture and lifestyle that she had been used to. He said:

So coming over here, in that setting, you have my mom who comes over here who is set in the old ways. So here she is helping wash dishes. She is trying to be helpful in the house because she knows there are no maids... Yeah, it's changed for her to see us okay... kids in America they are different - they are expressive,

but the household here because she knows she is visiting... So she is tolerant about the mess, so she will help clean up. (MAC.12.20-13.5)

Mac revealed that even with the cultural differences, his mom tried her best to assimilate by helping her kids with household tasks – things she was not used to doing in her home culture in the Philippines. However, Mac disclosed how his mom's absence of consistent place of residence was probably the most influential in impacting his mom's lack of niche or identity. He said, "She doesn't have a permanent place" (MAC.47.6). For Mac, his mother's withdrawal and lack of niche was a result of her having to assimilate to a new culture, and also because she was trying to integrate into system in which she had no permanent place to be – no determined role to fill.

Bo, from Family 2, also revealed his father's seeming lack of niche in his family based on his dependency on his wife to guide him in his social place. He said:

You know, unfortunately his wife's not there and it became very apparent to myself I mean anyone around him, my brothers and I in particular that my, how important my mom was in his life...she saw that things got done and she was the social organizer...they were partners in the true sense of the word, but she had her outgoing stuff that she ran and he was happy to come along and be sociable and it was organized and it was fun and they had a great life together. (BO.12.9-13.12, Seaman, 2014c)

Bo father's dependency on his wife to take care of him and socially coordinate his life was such an important motivator in his connection with his family and in his life. Thus, when his wife died, so did his niche or identity as a social being in his friend and family relationships. As indicated above, Bo's father lost connection with many of his friends after his wife died (JIM.17.20-17.23, Seaman, 2014d; BO.13.20-13.23, Seaman, 2014c),

and living in Florida, far away from his family, his father did not have his usual mainstays in which to connect. Therefore, his father's withdrawal, in Bo's opinion, may have been related to his father's dependency on his mother and thus not having a specific source to depend on.

Role reversal. Each of the families discussed how their parents' dementia progression caused their roles to reverse from being taken care of by their parents to taking care of their parents. Participants talked about role reversal as situations in which they had to tend to their parents' physical and mental needs as if they were kids, or situations in which their parents behaved as if they were children. This appeared as having to be responsible for their parents' daily routines and also as helping their parents emotionally regulate.

Erika and Patrick, in Family 3, discussed how caring for their mother was comparable to caring for a toddler with all a toddler's needs. Erika reported, "So right now I'm not caring for her, but when she was living here you know she was like having a toddler. You know it was 24/7" (ERIKA.1.27-1.28, Seaman, 2014e). Erika referred to the round-the-clock and daily care that she gave to her mom when her mom lived with her. She elaborated:

Um you know when she was here it was you know I always had to be thinking about stuff for her. Whether it was you know what pills are running out? Do I have time to go to *Marc's* tonight? Um you know, I can't cook this because she won't eat that... You know so it limited...our meals... She had to be my first consideration because she was the one that needed the most help...(ERIKA.65.23-65.31)

Like taking care of a two year old child, Erika had to be responsible for her mother's daily routine, as well as taking check of her mother's medical needs and meal preferences. Additionally, like any responsible parent's outlook would be for their children, because Erika's mom was most vulnerable, she needed to be first priority.

Patrick also shared his sister's perspective on role reversal in caring for their mother. However, he noted how his mother was like taking care of a child in trying to get her to get up and do things – like getting up in the morning and exercising her body. He said:

When they get older they are like little children and my sister used to try and get my mom to walk more and do exercises. Well then she's the bad person... the disciplinarian...then Erika would get the brunt of everything. (PATRICK.31.11-31.30, Seaman, 2014f)

Above Patrick remarked how in the process of trying to get their mom to do something that was good for her, their mom would become resistant to Erika's coaxing and then Erika would be forced to play the parental disciplinarian role. However, Patrick also experienced some of the child-like resistance of his mother. He reported:

Oh getting her up in the morning - oh my god it's a process. She is so hard to get out of bed. My sister goes "you have to start two hours early before you're going to leave because she is so slow." You have to physically go "mom you have to get up" every ten minutes go in there "mom you got to get up, mom, I'm not leaving, get up." You know fight with her "mom here's the toothbrush" you know "okay I'll do it in a minute." "No, mom, you got to do it right now." (PATRICK.45.19-45.24)

In Erika and Patrick's experience, simply going through the daily routines with their mother was reminiscent of taking care of children, with the 24/7 care, medication and

meal considerations, and just convincing their mom to get up in the morning. In other participants' experiences, helping their parents emotionally regulate was another situation comparable to childrearing.

In Family 4, Stevie and Mac discussed how their mom's depression over her breakup with her boyfriend had sent her in to a teenage depression and obsession. Stevie remembered:

My mom was always sought after. I don't think she has ever felt rejection in her entire life. No break up, no rejection and then for some reason this individual – it didn't last long, it was only three months... And then she was heartbroken and she went into a deep depression. At first we thought it was amusing - it was like a teenager. She didn't want to get out of her room, didn't feel like eating... Right and then umm she kept talking about it, which was actually good. She kept saying "I broke up with him" just kind of twisting the facts and then she became obsessed with him like she – okay, she started like texting and texting. We were like "if you want to move on just stop" and then we were like "no, but he's texting me." She started to say "no he's the one calling me." To make the long story short, we found out that he was trying to move on while she was constantly trying to get over him. (STEVIE.7.11-8.27, Seaman, 2014h)

Like being a teenager, Stevie and Mac's mother reacted with sensitivity to her break up that drove her to feeling so depressed that she would not leave her room or eat. Also, like a teenager, she became obsessed with contacting and re-contacting her former boyfriend, even after he had moved on. It became Stevie and Mac's responsibility to help their mother move past the break up and take care of herself again. However, with their mother's dementia, moving on became easier said than done. Mac revealed, "she had broken up with a boyfriend. When my dad died she met somebody and they broke off. It's been a year, but she thinks it was last week and she was calling the boyfriend for example." Even after a year, their mother still talked about her former boyfriend and the

breakup with him. As part of Stevie and Mac's mother's dementia, regular repeating of herself occurred. Yet, their mom's repeating of the trauma of breaking up with her boyfriend took her emotions to a different level, so much that Stevie and Mac, along with their other siblings, had to help their mother out of her depression and to emotional balance. Stevie, again, recalled:

We all went through that tough love telling her off "stop talking about - we don't want to hear it." We tried that we tried ignoring like pretend we didn't hear it. When that happened she'd be like "why aren't you reacting? Why aren't you saying anything?" (STEVIE.13.14-13.17)

Providing tough love to their mom in response to her repeating the story of her break up did not work for their mother, and even if it had, the chances of their mother remembering the insight was slim. Therefore, similar to raising a teenager, Family 4 experienced an irrational emotional state of their mother who because of her cognitive decline had difficulty shaking off the trauma of a break up. Moreover, emotional regulation became the responsibility of her children.

Formal care as a resource or another problem. The aforementioned superordinate clusters and their respective superordinate themes, by large, represented the involvement of informal caregivers (caregiving siblings) and their perceptions of their parents' experiences in the progression of dementia. However, participants also discussed the involvement of formal care in the caregiving system for their parents with dementia.

Three main ideas could be seen in participants' stories of formal care involvement in dementia caregiving to parents. First, in some cases, participants viewed the involvement of formal care as a resource: in other words, they believed that memory care

facilities, medical professionals, and staff were helpful and met the needs of caregiving situations (JIM.62.1-62.12, Seaman, 2014d; ZOEY.44.6-44.7, Seaman, 2014b). Second, some participants saw formal care as laden with problems. Participants reported being unsatisfied with information about dementia diagnosis, medical mistakes, and inconsistencies in the process of care (e.g., staff turnover, no clear schedules; ERIKA.15.8-16.2, Seaman, 2014e; PATRICK.25.12-26.25, Seaman, 2014f). Third, families discussed the problems of understanding and obtaining Medicaid/Medicare benefits. Concerns about eligibility and the costs that would actually be paid by Medicaid/Medicare were discussed in participants' stories (ERIKA.53.1-53.18, Seaman, 2014e; PATRICK.37.15-37.29, Seaman, 2014f; SHARON.5.2-5.20, Seaman, 2014j).

Initially, some participants talked about the benefits they and their parents received from formal dementia care. In Family 1, Zoey disclosed that after a gradual presence of formal care in the home, she and her brother decided to move their mother to a dementia care facility when it became clear that she could not assess her own safety (ZOEY.29.6-29.11). However, having moved their mom into the facility, Zoey expressed her satisfaction in the formal care for her mother. She said, "My mom, well, she's in a first rate facility. It's exclusively dementia care. And the staff is specifically trained to care for dementia patients. They're just fabulous" (ZOEY.44.6-44.7). For Zoey, what was of particular benefit was that her mother was in the hands of professionals who had been trained to work with people who had dementia.

Jim, from Family 2, also was pleased with the treatment that his dad had received from formal care. Specifically, he noted the personal qualities of the facility where his

dad lived. He said, “People know him there, he knows people there. Most importantly all his medical stuff is there” (JIM.61.10-61.22, Seaman, 2014d). Later on, he explained what a benefit it was to have the formal care community there for his dad’s medical needs. He explained:

...how do you create a whole medical- he’s got his skin doctor, he’s got his eye doctor, he’s got his general practitioner... They’re all right there, so yeah that’s, it’s like okay so it looks like that is where he is going to be. (JIM.62.1-62.12)

Furthermore, Jim noted, “I mean he is in a community that is supportive and he is in this kind of slipping kind of cognitive memory type” (JIM.26.6-26.7). For Jim, his father’s residence at the care facility meant that all his dad’s needs could be met – both physical and cognitive – which proved to be a significant resource in coordinating his dad’s medical management. Family 3 also shared their contentment in having medical management for their parent in the formal care facility. In particular, Erika from Family 3 pointed out how helpful the geriatric psychiatrist at her mom’s care facility was. She said, “And I think every family needs to have a geriatric psychiatrist because the only way to cope with this is to balance the medications” (ERIKA.49.24-49.26, Seaman, 2014e). Thus, balancing medications was another benefit to having formal care on-hand.

Other participants, nevertheless, talked about their disappointment and disillusionment with formal care of their parents. Oddly enough, Family 3 also experienced dismay in how medical management was handled. Erika and Patrick discussed the mistake made in prescribing their mother the wrong medication (ERIKA.51.11-51.24; PATRICK.27.1-27.3). Erika explained:

Um and then there was a horrible medicine mistake, which I could have sued for... Well Dr. Frankel had changed her medicine to something ... it's written in the other room. And the two spellings of the drugs are very similar. The one she's supposed to get is something like Toprazol... Yeah something very close. And so they started my mother on the wrong medication... My mom had been given this drug for maybe four days and it was a very strong painkiller. (ERIKA.51.11-51.24)

Erika further explained that one of the nurses caught the mistake after about a week, but nonetheless the mistake had been made. The medicine management mistake was just one of the problems that Family 3 had experienced in the formal care of their mom. In addition, Erika and Patrick noted difficulties in doctors and professionals diagnosing their mother, initially labeling her condition as an “altered mental state” (ERIKA.16.1-16.2), as well as problems with inconsistencies of care procedures (i.e., regular bathing) and staff turnover (PATRICK.25.12-26.25).

Nevertheless, the biggest problem with formal care seemed to be being able to obtain it through Medicaid/Medicare. In Family 1 and Family 2, participants' parents had saved money for their retirement that was paying for formal care involvement. However, the other families did not have the retirement funds to cover the high costs of formal care, and so had to rely on their Medicaid/Medicare benefits. Sharon, from Family 5, discussed the difficulties in paying for the needed formal care for her dad. She disclosed:

But basically it comes down to. There are very few people who, I don't know, in my mom's world you can't afford to put someone in a home and directly pay, which is 5 or 6 thousand a month... So your alternative is to keep the person at home and take care of them yourself and bring home health care in, which was an option. She investigated that or you go and take your case to Medicare and they have co-pay or but the fact that my father is a veteran, didn't really help... Financially. At a facility. So the battle was with was in proving that you're worthy or you – not worthy but that you qualify. (SHARON.83.29-84.28)

In Sharon's experience, Medicaid/Medicare was a benefit that could only be obtained by proving that the beneficiary was "worthy" of procuring it. Yet, in Sharon's father's case, it had to be proved that her father was poor in health and wealth to be able to qualify for Medicaid benefits. She added:

My mother [said], "well, obviously we have no income." Their income is retirement. From my father and my mother, her social security is her income... So the battle was to prove you qualify. And to keep some money coming in so my mother could live herself... And she, just struggled to understand it, all the paperwork and the forms and the calls and you have to work with Medicare people and schedules. Just trying to make it work and eventually she did make it work. I mean there was an issue with the house, she put the house in a trust for the kids when she first bought it 15, 20 years ago, and that was an issue with Medicare. You have to get rid of the house so she took the house out of the trust. They were going to count it as income and if they did, she would not qualify for Medicare. Turns out that they didn't. They ended up not counting it as income. We thought she'd have to sell the house to live on the proceeds...
(SHARON.84.14-84.28)

Sharon's experience exemplified other participants' perspectives on the difficulties of understanding and obtaining Medicaid/Medicare benefits to fund their parents' formal care. Yet, Sharon's case presented a situation that occurs when the spouse/partner of the family member with dementia is still living an independent life; her mother faced the possibility of losing her home in order to pay for the dementia care for her husband. In this way, formal care became even more of an obstacle, and less of a resource, in the process of caring for participants' parents.

In the stories of individual care recipients, participants discussed a number of obstacles that their parents were dealing with in the progression of their cognitive decline. Participants discussed the impact of life events on their parents, the dwindling lack of a

role in the family, the reversing of roles, and the involvement of formal care to help parents. These made up the superordinate themes of superordinate cluster, Individual Care Recipient (Parent with Dementia – Internal). Still, participants also discussed how interconnected relationships in their families (including roles, generational connections, and support systems) impacted the dementia caregiving process. In the next section, superordinate cluster, Relationships that Carry Individuals (External) will be discussed.

Relationships that Carry Individuals (External)

The third superordinate cluster that emerged was Relationships that Carry Individuals (External). This cluster represented participants' and their family members' interconnections. Generally, participants talked about the history of relationships and interactions of loved ones, the roles family members played, as well as the support that had been provided through the years and into the caregiving process. Five superordinate themes emerged from participants' stories: 1) roles played through the years, 2) third generation connections in the family, 3) contracts between the generations or intergenerational themes, 4) support in the sibling system, and 5) the presence of a wide reaching support network.

Roles through the years. One of the most frequently talked about ideas in participants' stories related to the roles family members (including participants) played in the family over the years. This superordinate theme was based on recurring behaviors and goals that participants believed were important in maintaining the solidarity of the family. Participants discussed the roles their parents, their siblings, and their own roles they

played while growing up, and the realization that those roles had been maintained through the years.

Participants talked about the characteristics and connections that their mothers and fathers had in the family. To start, three of the five families noted how their moms took on leadership roles (MATTHEW.11.5-11.10, Seaman, 2014a; ZOEY.8.2-8.3, Seaman, 2014b; BO.12.21-12.25, Seaman, 2014c; JIM.14.18-14.20, Seaman, 2014d; KEVIN.27.24-27.26, Seaman, 2014i; SHARON.57.9, Seaman, 2014j). In Family 1, Matthew and Zoey recalled how their mom had been both a powerful woman in her community and in the family. Zoey remarked:

[Mom] was in charge of the intellectual stimulation in the family...My brother and my mother are very intellectual, by nature. My father and I lead with our emotions, and we were both – I am bright enough and my father was bright enough – but it was the emotional make up that caused us to be less-than in the family because really valuable people are rational and problem solvers and thoughtful. (ZOEY.8.2-8.3; ZOEY.9.1-9.5)

To Zoey, intellectual qualities equated with more rational thought and behavior, which was prized by her mother. Being an intellectual was important in the family and in her mother's work. Zoey explained, "that she was a brilliant and well-respected educator. In [her hometown] she was a teacher and a principal in an elementary school. And everyone in the community thought she was, and she was in the community fabulous. And she was, she was brilliant" (ZOEY.7.2-7.6). Matthew added to the picture of their mother with his story. He said:

My mom had been a very competent, powerful, even professional person. Uh, very well-established in the community. Very respected. Um, she was a school

principal for many years – a very accomplished, a very successful principal. She'd been a high school teacher for many years before that. She had taught at [a] University. You know, she was a very accomplished, professional person. (MATTHEW.11.5-11.10)

In Zoey's and Matthew's eyes, their mother had always commanded respect and attention, both in the family and in the community. On the other hand, they reported their father's role was to appease their mom and take care of the emotional regulation of the family. Matthew disclosed:

Yeah, I'm talking like from infancy. [I learned that] feelings are a bad, dangerous, threatening, out of control. Like my dad's role in this was – his favorite expression...his first question out of his mouth was always, in a loving way mind you, "is everything under control?" That's how he would say hello. He would say "is everything under control?" And he had to be reassured that everything was under control. Believe me, I had everything under control. (MATTHEW.27.19-27.25)

Zoey clarified this idea of emotional regulation. She said, "but my dad was extremely social and gregarious. He sort of filled that gap... He provided the emotional support in the family" (ZOEY.7.3-7.4). In their perspectives, their mother's role as leader in their family demanded the virtue of intellectual reasoning, but their dad's role as supporter was to fill in the gaps by providing the emotional guidance.

Other participants reported a similar dynamic of having a commanding mother running the family. Sharon from Family 5 recalled, "yeah, mom ran the house" (SHARON.57.9, Seaman, 2014j). Similarly, Bo from Family 2 reflected:

And since my mom wasn't around to like give him a sort of a compass, a social compass or a queue to what's right and what's wrong you know he's just doing

what he thinks is right... I mean my mom really provided a lot of support for him. (BO.13.24-13.30, Seaman, 2014c)

In Bo's family and Sharon's family, their mothers took on the leadership role and the responsibility of guiding how things ran in the household. In Zoey's and Matthew's family, their mom also took on the lead role in both her family and civic life. It is interesting to note that in Zoey's and Matthew's family their mother was the parent who had been diagnosed with dementia, while in Bo's family and Sharon's family their fathers had the diagnosis of dementia. The pattern that is particularly noteworthy is that the parent whose role was to provide the emotional and/or social support in the family was the parent who circumvented the development of dementia, while the parent whose primary role was to rely on his or her spouse for that support was the parent who developed forms of cognitive decline.

Regarding participants' fathers, in two families it seemed fathers were clearly in charge. In Family 4, Stevie and Mac discussed the traditional roles of their parents. Mac described the patriarchy in his family. He said, "It's the culture like umm it is a very paternal society like the dad is this... So parents are always, you don't talk up or shout at them" (MAC.10.20-10.23, Seaman, 2014g). He went on to describe his dad as a "family man" judging from the seven children he had (MAC.36.2). Furthermore he noted:

...he was a heavy smoker – drinker...My mom would feel small sometimes because [my mom] being a socialite, sometimes he would say the wrong thing on occasion. But they were very loving; we celebrated their anniversaries very well. My dad believed in that. My dad was very religious in his final years. (MAC.39.9-39.13)

Mac's father was the head of the household in his perspective, but seemed to be happy in filling the role of the "family man." Stevie added to the description of her father's leadership role by contrasting his with her mother's role. She said:

Umm my mom's always has been again not the take charge, not the independent... My dad spoiled her, made her quit her job when he married her... Well she was, when she graduated from college she was working in a bank and my dad was the old-fashioned "no you're going to stay home and raise the kids." So all her life she has been this leisurely woman who raised the kids. But back in the day she wasn't really hands on. In Manila we had helpers, certain nannies. (STEVIE.14.31-14.34, Seaman, 2014h)

Stevie described the "paternal society" that her brother mentioned as one based in old-fashioned views of mothers' and fathers' roles in the family – mothers stay home and raise the children, and fathers work and take care of the family. In contrast to her father's take-charge role, her mother's role was to live a leisurely life, responsible for the children (with the assistance of hired helpers) and dependent on her husband. Moreover, she explained how significant her father's views of roles were in how he led the household.

Erika and Patrick also described their father's role as leader in the family. Erika disclosed:

...my dad was chauvinistic to a degree that he didn't think she needed to drive. If she needed anything, he would see that she got it. However, he worked at the [Local Newspaper] and worked nights. So he would work all night... So when it was grocery shopping – it had to happen in the morning when he came home from work – he would take her... Right and when I'd say to her, "mom why don't you... why don't you learn to drive?" [And she would say,] "Oh your dad doesn't want me to learn how to drive...No," she said, "he thinks that if I drove I would never be here. I would be gone." (ERIKA.10.17-10.23, Seaman, 2014e)

Similar to Stevie and Mac's father, Erika's father had a traditional view of the roles in the family, such that he took on the leadership of the overall functions of the family, while his wife took the traditional childrearing roles. Erika described how her father's leadership role was so influential that he could dictate when his wife left the house and where she would go. Patrick, also, corroborated his sister's story with his comparison between the roles his parents played. He said, "[Mom] was just a stay-at-home mom who took care of the kids and took care of the house... You know [Dad was] the breadwinner, he's the worker..." (PATRICK.18.18-18.21, Seaman, 2014f). In both families, the fathers took on leadership of the family organization, while the mothers took on the dependent roles reliant on the direction of their husbands. Again, the pattern that was mentioned above was represented – Stevie's and Mac's mother, as well as Erika's and Patrick's mother, both had played the reliant and dependent role in the family through the years, and both had developed forms of dementia. In a sense, the roles that parents took on seemed to balance out – where one parent took on the emotional leadership, while the other parent took on the logistical leadership – and thus not only balancing roles, but also perhaps balancing complicated family dynamics.

In addition to discussing their parents' roles in the family, participants talked about their siblings' roles while growing up. Some participants recalled the balancing of roles among their siblings that led to a sort of harmony in the family. Matthew disclosed:

In other words through high school, before we each left the nest, and so forth we were, what I think of in hindsight, as a typical, middle class, suburban American family, you know, a mother, a father, a boy, and a girl, and a dog, and a station wagon in the drive way and that sort of thing... We did not have a picket fence, but we had an apple tree in the backyard, with a barbecue. It was somewhat

idyllic to my looking back... We had a good life and so forth. And my sister and I were sort of just, you know, we got along fine. (MATTHEW.17.2-17.13, Seaman, 2014a)

In Matthew's perception, he remembered an idyllic childhood in which he and his sister had all they could want, including a solid relationship with each other. Zoey also remembered the positive relationship that she had with her brother. She said:

Because my brother, admittedly he will say this, was the golden child. And I don't know why, I don't know why but my brother could have taken that role and trashed me... He ran interference for me from the time I was tiny. And I felt I could always trust him, and that he would always be there for me... Um, yeah. We were very close. (ZOEY.8.17-8.24, Seaman, 2014b)

For Zoey, she remembered a childhood of differences in which her brother was favored as the "golden child." However, even with the apparent partiality by her parents, she believed she had a close relationship with her brother because of the care, loyalty, and trust they shared.

Although other participants noted differences in roles of their siblings, they discussed these differences in regards to how they led to seeming imbalances in family dynamics. Kevin from Family 5 disclosed how some of the roles his 12-person family led to strain and some led to harmony. He revealed, "Well, it's tricky because there's 10 of us, and we all have different roles, and we all have different relationships with my parents. Some are a little more strained than others. Mine was, I had good relationships with my mom and dad" (KEVIN.3.21-3.23, Seaman, 2014i). In Kevin's view, the different relationships that had been created between his parents and the children in the family contributed to strain or harmony between different family members – and

ultimately the roles they played in the family. He went on to clarify that having common interests with his father helped to build a stronger relationship and more defined role in his life. He said:

...He coached me when I was a kid. He didn't have time to coach anybody else, because everybody else... There were so many kids... So, my relationship with him was different than Sharon's would be, than anybody else's would be. Because he had time for me. Or, a little more time than he had for any of the other... He may have coached some of the other ones, but I get a sense that it wasn't nearly as enjoyable as my experience was. And, we went to the same High school, so we have a connection there. And, then, I would take him to see football games. [High School] games. He and I would do, you know we would go wherever they were playing and we'd go see them. So, it was just a nice... He and I would go do these things... [On the other hand] Jsister... No, their relationship is not like mine... Theirs was contentious. (KEVIN.7.1-7.22)

Kevin described a harmonious relationship with his father. However, he noted differences in connections of his father with his siblings, most likely due to there being so many children to keep up with, but also relating to conflict in the relationships. Additionally, Kevin alluded to the notion that the roles siblings played in relationships with their parents and sibling, at least in part, may be due to levels of connection formed with each other.

However, underlying participants' discussions of roles was how those roles had been maintained through the years. Stevie and Mac from Family 4 discussed the role of a tight-knit family that their family members had played while growing up and into the current caregiving process for their mom. Earlier, it was noted how the closeness of Stevie and Mac's family was present while they were growing up, so much that they and their friends referred to them as Team-Tom (STEVIE.19.14, Seaman, 2014h). She

reflected, “Among siblings we are always very polite to each other, always open to hearing what the other person has to say, or if you know there is a little bit of a disagreement we learn to disagree – [for example we would say] “oh that’s not what I meant”” (STEVIE.18.10-18.12). From Stevie’s perspective, part of playing a part in her tight-knit family was respectfully communicating with each other – something that she and her siblings had learned while growing up and used in their current roles as caregivers to their mother. In addition, Stevie noted how her role of big sister had been maintained in her current relationships with her siblings. She remembered, “I was more follow-the-rules-conservative, you know, “square peg”... But like I said now that we are dealing with our mom... I am a life coach. I try to frame my words and the affect I have... I try to use these strategies and so we now talk a lot more often” (STEVIE.17.25-18.7). Stevie recalled how she was the one to follow the rules while growing up, but also how she maintained that role to help her family communicate through the structure of interaction that she used in her work as a life coach. Yet, she further reflected:

...There is that financial thing; it is a real thing. That’s where I hope [my siblings and I] are still on the same page. It can cause anxiety... Well, going back to our norm, our culture how we were raised, there is all this politeness until [my younger sister] told me – oh my god I was just not sensitive enough to know that.... Like me being the eldest sister I should have known that she was spending that much [on caregiving for mom] but she doesn’t say anything until the last minute. So there is again this whole diplomacy. (STEVIE.34.26-34.28)

Stevie gave consideration to how her role as a member of her tight-knit family was to be connected and communicative about what was happening in her family and as collaborator with her siblings in taking care of their mother. Yet, she also revealed her

expectations of herself in her role as eldest sister to be aware of the needs and concerns of her younger siblings.

On the other hand, Erika and Patrick from Family 3 revealed patterns of conflict in familial roles over time. Erika recalled the conflicting roles of her younger brothers, which she stated she had not been very aware of when she was younger because of the age differences between them. She said, “I think there was some sibling rivalry when they were growing up...But when I was away at college, if they had their spats, I was never aware of it but apparently they did. Maybe KBrother was telling me about it. And so they were never close” (ERIKA.20.20-20.26, Seaman, 2014e). Patrick, also, confirmed the rivalry that influenced their roles through the years. He disclosed, “you know me and Kbrother, we never really got along anyways” (PATRICK.7.12-7.13, Seaman, 2014f). Patrick also noted how even in their current roles as caregivers to their mother he and his brother were in conflict about who did more. He said, “I would cut the grass most of the time, you know my brother, Kbrother, would tell you that he did it. We would get in fights about that” (PATRICK.9.2-9.4). Furthermore, Patrick discussed how the conflict between his brother and him had gotten so intense that they were no longer speaking. He added, “Oh yeah Kbrother and I don’t speak at all... I don’t even know if he visits her” (PATRICK.41.10-41.12). Thus, in Patrick’s and Erika’s family, a pattern of role conflicts that were created in childhood continued into adulthood in the roles that siblings took on in the care of their parent. Moreover, in both Family 3 and Family 4, role patterns that existed while growing up persisted into their current roles, whether they represented

balanced and harmonious roles or those filled with conflict – roles were maintained through the years.

In a similar but different way, Sharon and Kevin from Family 5 disclosed how roles had been maintained, but that they observed that their perceptions of family solidarity had changed. Sharon discussed how the relationships and roles that her siblings played in the family had been maintained. She revealed:

I can only say that I think the relationships are pretty much the same as they were...I think I'm still, look I was close... all my sisters when I was younger and I still am. But I think the difference is that we really didn't hang out much together as we were growing up... We lead different lives... I don't think we have changed much. I think my, my perception of our various relationships has changed. Because I thought that we would always be close, tight, like be us against the world and that's not how it is and we are...we kind of fragmented...some literally moved away and some got married and our lives changed so now we're not so, we're not like this anymore... (SHARON.51.27-52.20, Seaman, 2014j)

Sharon reflected on how while growing up her siblings lead different lives, but how they maintained relationships of closeness and looking out for one another. Yet, even in her and her siblings' current roles they continued to live separate lives, but Sharon's perception of closeness had changed – she began to see that the closeness that she once saw between her siblings was no longer there.

Kevin's point of view also supported Sharon's perception of the fragmentation in roles in the family while growing up and into adulthood. He described the naturally occurring shifts of roles and relationships in his large family. He remarked, "with 10 kids, there's always different levels of, someone's not happy, someone's happy, someone pisses somebody else off, mom's mad at this person, and dad's not doing, it just goes

round and round” (KEVIN.10.10-10.12, Seaman, 2014i). In his point of view, the differences between his siblings were related to the generational disparities, as well as variability, in his siblings’ proximities to their parents. Additionally, he noted how the differences had persisted in current roles in the family. He said, “I think about it in my family as [*sic*] there is two generations. There’s the older 5 [many of which remained local] and the younger 5 [many of which live remotely]...So, yeah, you would think the people closer would be more connected to the ones on the west coast... Cbrother and Asister, they make a much better effort than some of the local people at staying in touch” (KEVIN.17.6-17.23). Like his sister, Sharon, Kevin also came to the realization that the roles that his siblings played in the family did not necessarily guarantee connection to the family. In fact, he observed that his expectation of his siblings that lived locally to be in more contact with the family and the care of his father was invalidated to a point, because it was his siblings that lived further away that seemed most involved in their caregiving roles.

All in all, participants described various roles that were played through the years in their families of origin. Related to their parents, participants revealed differences in leadership and emotional/social involvement in the family through the years. Related to their siblings, participants recounted stories of role collaboration and conflict. However, underlying all the roles was a pattern of role maintenance through the years. Whether the roles developed in childhood were positive and harmonious or negative and conflicted, participants revealed that the roles had not changed over time. Yet, Family 5 uncovered that possibly what changed through the years was family members judgments of the

roles. Still, role maintenance and perception changes were not viewed in a vacuum – indeed, other relationships existed that carried individuals through the years – namely, the impact of third generations (i.e., siblings’ children) on the family and care of parents with dementia.

Third generation connection. Another superordinate theme that emerged in the Relationships That Carry Individuals superordinate cluster was a pattern of connection and support with third generations, specifically the grandchildren in families. Generally, this represented the presence of participants’ and their siblings’ children in the family and caregiving process. Participants discussed their children’s involvement and contributions to the family, as well as their aging parents’ responses to their involvement.

Participants talked about their children and their siblings’ children in regard to important things they were doing in life and their involvement in the family. In Family 2, both Jim and Bo noted the involvement of the youngest grandchild in activities of the family. Jim recalled the personal connection he had with his nephew (the youngest of the grandchildren) because of shared interests. He remembered:

...Actually what has emerged in the last year is my nephew [will call me up and say] “Uncle Jim, when are you coming down let’s do some jamming?”... he plays trumpet... But he’s been taking guitar and he’s, so he reads music and he’s very focused and very intense with it... So he called me up and... he says, “Uncle Jim I am going to be taking ... a Rock n’ Roll band class at high school”... “Is it okay I take the guitar you – that I have down here?” I lent him a guitar... I said, “as long as you don’t burn it on the stage”... I said, “consider it yours ... just don’t burn it on stage.” (JIM.76.12-77.21, Seaman, 2014d)

Jim joked with his nephew about parameters of borrowing the guitar he lent him. Yet, his story of the connection with his nephew underlined the continuity in relationships and

connections that unified his family. Jim's nephew was the only child of Rbrother. Yet, what is important to note is that Jim had discussed that his connection with Rbrother was minimal because of different worldviews and general approaches to life (JIM.11.20-12.15). Thus, having the relationship built with his nephew linked Jim to Rbrother. Jim even noted Rbrother's and Rbrother's wife's approval of the connections. He recalled, "and I think RBrother - both RBrother and [his wife] Susan -- are really appreciative that we have that connection with his kid. I mean who could ask anything more than have your sibs like your son" (JIM.83.17-83.19).

Jim's brother, Bo, also discussed the connection he had with his nephew. He said, "Yeah so I try and give [my nephew] whatever I can; and he is -- sometimes I'll say, "I'm coming over and I'm having dinner or lunch with grandpa do you want to come?" He'll say, "I'll come. Anything to get away from my parents"" (BO.32.19-32.21, Seaman, 2014c). In Bo's perspective, not only did the relationship serve as a link between is brother and him, but also Bo saw value in what he had to offer to his nephew, thus emphasizing the importance of the third generation connection.

Another way, and probably the most frequent type of third generation involvement that participants discussed, was the contribution that grandchildren made to the caregiving process. In participants' perspectives, grandchildren contributed by visiting their grandparents, making observations and advocating for their grandparents, and providing opportunities for family members to come together. For example, Matthew and Zoey from Family 1 discussed their appreciation for their children's efforts to visit and connect with their grandmother during the holidays. Matthew recounted:

But the grandchildren, when they come to [town], they definitely will see their grandmother, for sure. My niece and two nephews were recently in [town] for Thanksgiving and they all visited with their grandmother. She came [to our house] for Thanksgiving dinner; And those three grandchildren and their significant others who were here also spent time with my mom, as do my kids, when they're here. (MATTHEW.4.15-4.20, Seaman, 2014a)

Matthew went on to add, "And we told them, when you see your grandmother, exaggerate "Grandma, it's so great to see you!! I'm Agranddaughter!" to help her remember... And that kind of seemed to work as far as we could tell" (MATTHEW.23.1-23.4). Zoey confirmed this response and validated the grandchildren's efforts to connect. She said, "Yeah. And I mean all of my kids came in for Thanksgiving. And they visited her; we brought her here for Thanksgiving dinner. My kids were fabulous" (ZOEY.33.27-33.28, Seaman, 2014b). Thus, in Matthew's and Zoey's perspectives not only did the grandchildren make an appearance, but also they made efforts to connect with their grandmother who may have forgotten their names and who they were. In this way, they contributed to efforts in the caregiving process, but also provided a third generation link in the unity of the family.

Other ways that grandchildren contributed were by vocalizing their observations and advocating for their grandparents. Stevie from Family 4 discussed how her children were instrumental in helping her and her siblings understand the level of cognitive decline that their grandmother was experiencing. She recalled, "and then more and more and even the girls would notice, my kids [would say]..."Mamita mamita you asked us that again." They would do it in kind of a light way; and then umm just this last visit to the Philippines last December or January we realized it's really progressing"

(STEVIE.11.1-11.8, Seaman, 2014h). Stevie noted how her kids would respectfully point out to their grandmother when she was repeating herself. Additionally, she observed that it was her children's gentle feedback that first alerted her to their grandmother's onset of dementia.

Erika from Family 3 also noted her niece's help in observing and advocating for her grandmother. She remembered:

And then maybe a couple of years later [my mom] had an episode where she wasn't eating regularly enough. And her blood sugar dropped and by the time Patrick got to the house – because my niece was talking to her on the phone and ... long distance and my mother's speech was slurred. And she called her dad, Patrick, and said "there's something wrong with grandma." Patrick went over there. She was slouched in her chair. And she was clearly slipping into a diabetic coma. He calls the squad. They take her to the hospital. (ERIKA.13.33-14.3, Seaman, 2014e)

Erika pointed out the instrumentality of her niece in getting the assistance that her grandmother needed in the imminent situation of a diabetic coma. Her niece recognized a change in her grandmother's voice and acted on it by alerting her father. Her niece's initiative in advocating for her grandmother was not only evidence of her support in the caregiving process, but also confirmation of the important role she filled in third generation connection.

One other way that third generations contributed were in the unity they created within the family. In particular, Patrick from Family 3 recalled how his niece planned a holiday get-together at her house as a neutral ground for her uncles to come to be with the family. He recounted:

So...where was it... they had a pre-Christmas thing at Erika's Daughter's house... She had a holiday thing; and everybody was going to be out of town, so she had a holiday thing; Kbrother was going to be there...it was awkward, but I just kind of avoided... you know Kwife, his wife and my wife will talk, but not outside of the group setting but just because they are there... [they were] cordial. (PATRICK.15.9-15.19, Seaman, 2014f)

From Patrick's account, his niece made the effort to bring the family together, which he openly admitted was "awkward." Still, he went along with it, and reflected how even in the conflict with Kbrother, family members were able to be cordial. Thus, Patrick's niece contributed by providing a neutral ground for her family members to exist on – temporarily assuaging the conflict, unifying the family, and underscoring the importance of third generation connection in their role of carrying the family in the caregiving process.

Contract between the generations/intergenerational themes. Another generational theme emerged in participants' stories with regard to intergenerational expectations, or what one participant coined as a "contract between generations" (JIM.66.1, Seaman, 2014d). This intergenerational theme was characterized by filial expectations and culturally prescribed modes of conduct of how and who would care for elders in their aging years. Participants discussed the importance of honoring family expectations of care, reflecting on their own expectations of filial care from their children, and how their cultural heritages influenced caregiving behaviors between generations.

Initially, participants talked about how family expectations impacted their beliefs of how they would care for their aging parents with dementia. In Family 2, Jim discussed

his desire to care as a privilege, but as part of the contract he had as an offspring of his parents. He disclosed:

... it's a privilege, like I said. I am very privileged to be able to do it. Uh, we're all okay with it; it just seems like this is what we do at this point in our lives... in sociology there is a concept, it's called a contract between generations... And that is what that is, it's a contract between generations. It's like when you're little and need care we give you care and you give me care... and it's sort of determined by the quality of the relationship or your sense of obligation. (JIM.65.20-66.11, Seaman, 2014d)

Jim described the concept of the “contract between generations” as a contract of reciprocity in caring – because his parents cared for him and took care of the family while he was growing up, he then felt it was his turn or duty to care for his parents as they grew old. In addition, he noted that this *contract* could be determined by the relationship quality between aging parents and adult children or caregivers’ sense of responsibility to the family. Adding more insight, however, Jim discussed another influence on the contract between generations. He disclosed, “yeah so it just seemed like it was time and also it was somewhat modeled on my parents taking care of my grandparents” (JIM.66.17). Jim discussed his memories of his grandfather living a few houses down from his family home and how his parents would take turns going over to his grandfather’s house to care for him. He relayed how he and his father have reflected on the parallels in caregiving experiences – for example when checkbook responsibility was given to the adult children and when driving privileges were ceased. In Jim’s point of view, the contract between generations was one that was not only based on felt privilege

and expectations, but also it was a modeled behavior handed down through the generations.

The contract between generations was also discussed as a way to honor the legacy of family members. In Family 1, Zoey explained that the expectation to care for her mom came from her desire to honor her deceased father. She said:

I cared for my mom to honor my dad...Because it was very... I'm shaking my head... it is very hard to care for somebody who never says thank you. Ever; who has no appreciation for what you may be putting up with; and who continues to be critical and judgmental... And I said, "I am doing this because it is what dad would expect." (ZOEY.24.18-24.27, Seaman, 2014b)

In Zoey's experience, reciprocity of care was not the impetus to support her mother through the debilitating stages of dementia; after all, she had lived a long history of feeling unappreciated, judged, and criticized by her mother. Rather, knowing that her father would have expected filial care to be given (he was the emotional support in the family – see the aforementioned discussion of the superordinate theme, Roles Through The Years) was incentive enough. She went on to add:

Just – the last year was terrible for me because, oh god, on so many levels if I ever had a fantasy that me and mom would be able to reach a resolution in our relationship... And anger at having to care for her when she never cared for me. And guilt that I could care for my father – and I mean physically care for my father, lovingly – and that I could, I had to make myself... It was an obligation [to care for my mother]...And that felt really crappy. (ZOEY.29.13-29.18)

Zoey noted her inner conflict in caring for her mother – on one hand, she remembered providing care to her father, lovingly and without hesitation when he was ill; on the other hand, she felt total obligation to care for her mother in her ill state, with thoughts of anger

and ambivalence about doing it. For Zoey, the contract between generations was built on honoring her father and everything he stood for, but not as reciprocated act toward the woman who she grew up with.

Many participants discussed the idea of an intergenerational contract as a way they and their siblings would give back to their parents out of a sense of privilege or reciprocity, or as a way to honor parents they loved. However, Sharon from Family 5 discussed the unmet expectations she had about the contract between the generations for care. Sharon conveyed the closeness and bonding that her siblings had while growing up, but also when their father first developed signs of dementia (SHARON.31.6-31.21, 52.13-52.17, Seaman, 2014j). However, she also expressed her surprise when her siblings did not follow through to help with the care of their father. She revealed:

I think I've come to terms with it but it's hard because I expected more, more support...more camaraderie, more plugged-in, more like, you know, I guess I kind of expected my sister to say, "Yes, I'm moving home." The one in Canada. "This is a big deal and I want to be there for the family"... Like my brothers would say, "Yes, I'm taking a leave of absence from work, coming into town and we're going to figure this out together." But in the past, I think that's what they would have done, in my brain. But now, no, they didn't do that and I'm kind of like, "why not?" "This is a big deal and we're doing this together"... But they didn't see it that way and I was a real, kind of a...it was kind of crushing... That was a real change 'cause when we were kids, even when we were, even five years ago, they would have said...I think even in my head, they would have come. (SHARON.53.1-53.27)

In Sharon's experience, the contract between generations was something she and her siblings had talked about in theory. Nevertheless, when it came to the reality of caring for her father, the contract fell short and the responsibility was in her hands. In her case, even though the expectation was there – discussed by all the siblings – the follow through was

not, leaving Sharon with missed expectations, hurt feelings, and bewilderment. Even she noted the sacrifice she made to stay close to home to assist with the care for her father. She conveyed, “I was unemployed three years ago, and I could have taken this job out-of-state and I didn’t, because this thing was looming... And I made that decision to stay here. To take care of this, help with this” (SHARON.53.16-53.19). In her mind the decision to help her father was clear, and so when it came to the decisions of her siblings to stay put in their respective places, it came as a surprise. In Sharon’s family, contract between generations seemed to hold a different value among the siblings in the family.

Besides intergenerational themes related to how adult children would care for their parents, participants also disclosed their own expectations of filial care from their children. Matthew from Family 1 discussed his expectations of how he wanted to be cared for in his old age. He described:

And I’ve made plain to my children in the context of their grandmother what I am asking of them when I am older... I asked them to be as kind to me as we were to their childhood pets... “when mom and I had to put those dogs to sleep... You have not only my permission to do that, I’m asking you to do it”...I said at that point, “I’m not going to have the capability of decision making”...I said, “If it suits your purposes to keep your old senile old dad in the nursing home, because you want to come and visit, go right ahead. But that’s going to be for *your* purposes, not for mine. Don’t do me any favors...If there’s no point in keeping me alive anymore, pull the plug, please, I won’t care.” (MATTHEW.23.21-24.10, Seaman, 2014a)

From Matthew’s experience of caring for his mom he had developed his own perceptions of what his mother was going through in her dementia. Thus, he decided that he wanted to be able to make the decision for his children to be relieved of potential suffering, so

they would not have to deal with the struggle of caring for him in a mentally incapacitated state.

Erika from Family 3 also had ideas of the contract of care between her and her children. She expressed a desire to not be a burden on her children as she reflected on her experience caring for her mother. She revealed:

And I'll tell you what this whole thing has made me reflect on is...I don't want to live like that. I don't want that to happen to me... But I don't really want to...I don't ever want to have to move in with my children. And my mom didn't want to. She didn't want to move in... I took her against her will... And I don't want to ever do that to my kids but what...what is gonna happen to me and my husband in how ever many years if we start you know getting dementia? (ERIKA.67.24-68.6, Seaman, 2014e)

Erika's reflection on the burdens of caring for her mother revealed her desire to not put her children in a similar position with her own imminent aging. However, it also brought her fears about the future for her husband and her, how would they be cared for, and who would be involved should they experience cognitive decline. Both Erika's and Matthew's accounts of their experiences seem to speak to a greater societal question about the pros and cons of developing and growing old in an individualistic cultural framework – one in which those of us who are middle-aged already are feeling the burden of our existence on younger generations.

Following from that, participants reflected on how culture had influenced the contract between generations. In Family 4, Stevie and Mac described the filial expectations of care as rooted in their Filipino culture. Mac described the cultural expectations that influenced the contract between the generations. He observed, “Yeah

usually it's the daughter who would take care of the mom always. That's the culture" (MAC.48.7-48.8, Seaman, 2014g). Stevie's story added more clarification of the cultural conventions. She conveyed, "my brother's taking care of my mom now...but it usually it's the daughter. Usually your mom stays with the daughter" (STEVIE.35.6-35.7, Seaman, 2014h). Stevie and Mac recounted how in their Filipino culture parents in their elder years typically lived with a daughter of theirs. Yet, even though their mother was now living with one of their brothers, the cultural mores of younger generations caring for older generations was maintained. Stevie also noted that even though the cultural expectation was there, it was not always easy. She revealed, "It is also a big burden to take in even if it is in our culture to take in your elderly. Here in the States you put them in homes, but back home we take them in and it's not always easy" (STEVIE.35.26-35.29). Having lived in two different cultural schemes – her Filipino life growing up, and her U.S. life as an adult – Stevie had been exposed to different customs of caregiving. Seemingly, while living her adult life in the U.S. – oftentimes where aging adults are placed in formal care facilities – the Filipino cultural prescription for her mom to live with her was a difficult proposition to fulfill. Therefore, finding a balance between the different cultural demands of caregiving had become an important task for Stevie and her family.

Erika from Family 3 also discussed cultural traditions related to caregiving. However, she reflected on ideal states of caregiving and the differences between Western and Eastern cultures. She expressed:

And you know at the point we are in our lives. And I know a lot of people do this. And in the Asian culture, it's just what you do... You take care of your elders... And I feel guilty that I couldn't hang in there and do it the whole way. (ERIKA.53.14-53.20, Seaman, 2014e)

Erika had brought her mom into her own home to live for three years as her mom's cognitive and physical health began to decline (ERIKA.1.14-1.36). Yet, as Erika indicated in the above statement, the ideal situation would have been to care for her mother in her home until her mom passed on. Even though she had tried to maintain the ideal, she felt guilty that she could not see it through. Thus, Erika and Stevie shared the struggles of caring for their mothers with dementia within the cultural ideals of dementia care within the family versus dementia care within the formal care system.

In sum, what was discovered in participants' stories of intergenerational expectations of filial care was that the contract between generations was not as definitive as it may seem. Indeed, Jim from Family 2 seemed to have it right when he said that the contract was partly due to the relationships formed and levels of connection that existed between aging parents and their adult children. As represented in Family 1, Zoey highlighted the difficulty in caring for her mother who she believed never cared for her. However, the level of ongoing connection between siblings seemed to impact who and how they shared in the contract between generations. As Sharon from Family 5 discussed above, siblings did not offer the support that they may have promised in the contract between generations. Hence, support in the sibling system also emerged as an important part of the relationships that carried individuals.

Support in sibling system. Earlier in this chapter, under the superordinate cluster Individual Caregiver (Internal), the theme of Sibling Closeness/Unique Bond and Alliance was discussed, featuring ways that siblings connected with each other beyond the caregiving responsibilities of their parents with dementia. Additionally, in this section, the roles family members played through the years were discussed. Participants talked about the roles their parents and siblings played, which in many cases represented the closeness of relationships between family members. However, a different theme emerged related to participants' perceptions of support to one another. In some cases, participants talked about the instrumental support siblings provided in the family system, including delegating responsibilities, taking turns in caregiving, and supporting roles. Most often, though, participants discussed their experiences of emotional support, having a common goal, and opening lines of communication.

On a basic level, participants discussed the ways they instrumentally helped each other with caregiving tasks, contributed to each other financially, and supported each others' contributions to the system of care for their parents with dementia. Patrick from Family 3 discussed the delegation of tasks to support his sister who was taking on the routine caregiving of their mother who was living with her. He said:

Yeah [Erika] goes "she (mom) can't stay here by herself"... god bless her for doing that you know. She did it in, it obviously talking to her I was never in that role where she lived with us ever. I mean since years and years obviously so Erika took that on and got to see day-to-day what that was like... She was with my sister over three years...well my sister wanted a break periodically. So we all agreed that on Saturdays we would take turns and came up with a schedule and then Gbrother took over. He made the schedule and we would take turns picking her up so my sister would get like a day off. (PATRICK.3.20-4.10, Seaman, 2014f)

Patrick's account of delegation of roles and sharing of responsibility with his siblings in caring for their mother exemplified the provision of instrumental support. He and his brothers collaborated to help their sister by giving her a break from the routine caregiving she provided to their mother. More notably, he recognized the intensity of the day-to-day job that his sister was doing, and reached out to provide her instrumental support with daily responsibilities of caregiving.

Bo from Family 2 also spoke of instrumentally supporting his brother who had taken on routine tasks of caregiving. He began by explaining the responsibilities of his older brother. He said, "we have the same concerns and he's sort of more in it because he's viewing the financial, he's got his hands in the financial stuff... Yeah it was sort of delegated to him, but as yeah, it's his baby" (BO.55.8-55.11, Seaman, 2014c). Bo noted that although he had the same concerns about his father's care, his older brother was delegated the financial responsibility in caregiving. He went on to explain:

...so supporting each other...Jim has [Dad's] tax stuff and we're like okay this one goes to a post office box [to the City], this one goes to a different post office box to the IRS [City taxes], this one goes to the [State], and this goes to the [Town]. So how do I support? So I write the envelopes out... Jim's making sure the checks are in, I'm writing the addresses... Well yeah that's the idea....that is sort of my understanding of what we're supposed to be doing as a family...In supporting each other... (BO.62.7-63.18)

Bo's account highlighted the collaboration and sort of back-up support that he gave to his brother Jim, who was taking on the routine financial tasks of caregiving. Yet, for Bo it seemed that more than helping his brother with circumscribed duties, he had a special interest in preserving the unity of the family, and by that supporting his siblings.

Participants talked about the unity and connection that they felt with their siblings in the caregiving process. Both Matthew and Zoey from Family 1 discussed the unity they felt in how connected and emotionally supportive they were to each other. Matthew reported, “The relationship has always been there all along, and it’s available to each of us. Dealing with our mom’s, as you say, cognitive decline. You know that’s just the latest chapter in something else we’re both sharing” (MATTHEW.18.20-18.22, Seaman, 2014a). In Matthew’s perspective, the emotional support that he and his sister provided each other was a continuation of the support that they had always maintained. He went on to add:

I think it has to do with two things. One is the emotional support that has to do with navigating the relationship with our mom, who’s a piece of work – there’s no doubt about it. I mean our mom is a challenge at times. (MATTHEW.19.26-19.28)

Ostensibly, emotional support was helpful not only in maintaining the sibling bond that had always existed between Matthew and Zoey, but also it became an important tool in dealing with the changes that their mother was facing with her dementia. Specifically, Matthew recalled:

[Mom] would get angry and lash out. And it would come out in the form of really, not really nice behavior and insulting behavior, and I would oftentimes just let it roll off my back. But my sister would later say, “Can you believe what mom said about you!” You know, and that’s support. At least somebody else [laughing] somebody else recognized it too! (MATTHEW.21.3-21.7)

Thus, another way emotional support was provided was when dealing with the criticism from their mother. In Matthew’s experience, Zoey was there to validate him in the

feelings he may have experienced after being judged and ridiculed by his mother. It was an appraisal that he had indeed endured unnecessary and harsh criticism from his mother, whom he spent so much time and consideration in caregiving.

Kevin from Family 5 also discussed the importance of emotional support in the way of unconditional acceptance for his siblings and their contributions in the caregiving process. Kevin disclosed:

...and you accept it. I mean that's why I don't have any issues with my brothers or sisters. I just accept them for who they are and I just hope that when things get rough that people step up as much as they can... that's all you can expect... (KEVIN.35.10-35.12, Seaman, 2014i)

Seemingly trusting his siblings to take initiative in the caregiving process was support enough for Kevin – and extrapolating, one might guess that this kind of acceptance would be supportive to his siblings, as well. Kevin further relayed:

Yeah. I mean [my oldest sister] and I aren't super close, but I'm happy to see her. Whenever we are together we chat for a little bit. So, I am at a point where I'm not really disagreeing with any of my [siblings].... I'm just happy to have them... with my crazy life the way it is and the experiences that I've had. It's like hey you know we're all in this together so do whatever you can. (KEVIN.37.22-37.26)

Kevin's reflection on the complications of his own life – and knowing the complexities of his siblings' lives too – helped him understand that even though they may not be close in proximity or actively engaged in each other's lives, that they were still a unit and “all in this together.” Thus, emotional support was provided in the unconditional acceptance that was provided, the trust that siblings would do what they could, and also in understanding

the complications of each other's lives. Still, Kevin touched on another important way siblings supported each other – knowing that they were working to common goal.

Participants talked about the support that they gave to each other in service of a common goal. Jim from Family 2 conveyed his intentionality of being on the same page with his brothers in the caregiving process. Jim reported:

So, because it is really important to me that we are all on the same page... It's like we are going to talk about this together because so so (laughter) something we don't have an opinion about it, like when it happens, or it's not a crisis when it happens. The plan is the plan is the plan. (JIM.19.5-19.12, Seaman, 2014d)

Being able to have a common goal in the caregiving situation worked as a way to bring his siblings together. Nonetheless, it also provided a safety measure in preventing any crisis situation. Still, Jim noted that a significant reason for being on the same page was about equal sharing of information. He stated:

And I mean the other thing I do is, is like there's just trans-, I'm a big believer in transparency especially if I am in the financial stuff. I said this is this month and here he gets statements, I say this is where we are you know so that everything I do is transparent. Nothing is mysterious. (JIM.59.22-59.25)

Transparency was of utmost concern to Jim, and he wanted his brothers to feel that all the financial information for their father was on the table – that there were no unexplainable liberties that he was taking without discussion between his brothers. Furthermore, for Jim, being transparent was a significant part of maintaining that he and his siblings had a common goal in the care of their father.

Having a common goal was a supportive element that was also helpful to Family 4. Stevie discussed the importance of being on the same page not only with her siblings, but also with her mother's sisters. She revealed:

...because we all live in different places and to streamline communication so you don't have to repeat yourself. What is the latest update on my mom and to get my aunties involved and just to have everybody on the same page. (STEVIE.30.1-30.4, Seaman, 2014h)

With her siblings living in various parts of the world and her aunts living in the Philippines, Stevie's perspective was that it was important to not just get her immediate family on the same page with her mother's care, but also to involve her aunts. Earlier in Stevie's story, she had noted the close relationship that her mother had with her sisters, and the influence they had on her well-being (STEVIE.20.27-20.31). Thus, knowing that influence, Stevie found it important for them to be on the same page as well. Nevertheless, as can be seen in both Jim's and Stevie's accounts, part of achieving the common ground was opening lines of communication.

The most talked about mode of sibling support was in the lines of communication they built with each other. Sharon from Family 5 recalled how supportive it felt to just be heard by her brother. Sharon revealed:

[Kevin] is connected. He does call my mom and sees how she's doing. He does call me. He asks me how Dad's doing. "Do you need me to come out? Is everything okay? Do you need anything?" I can call him and talk to him about it. (SHARON.30.18-30.21, Seaman, 2014j)

For Sharon having her brother open the lines of communication was a source of support. Not only did he ask about the instrumental needs of his father, but he wanted to know how Sharon was doing and if she needed anything. She reported that it was a sign that she could open up to him about what was going on.

Mac from Family 4 also discussed how opening lines of communication was a crucial mode of providing support. In particular, he noted how the use of technology was especially important for his family. He disclosed, “So at this stage we are getting there to that you know as you say we are all globally rooted now and are coming together through the use of technology to put everything down and decide as a family” (MAC.45.12-45.14, Seaman, 2014g). He goes on to add, “I think regularly with technology almost everyday we are talking about what is going on” (MAC.69.4-69.5). Technology had become a practical way for Mac’s siblings to connect and make decisions as a family. In addition, it made communication regular so that connecting with each other was done daily, thereby opening lines of support to one another.

In summary, participants viewed sibling support as both instrumentally and socially supportive. Siblings not only assisted each other by doing instrumental tasks, but also helped each other through emotional support, coming to a common ground, and fostering lines of communication; they supported each other in relationships that carried them through harmonious and conflicted moments. Like third generation connections, sibling support worked to unify the family. However, siblings and third generations were not the only sources of support. There also were wide reaching support networks available to all parties in the dementia care system.

Wide reaching support network. A final superordinate theme that emerged in participants' stories about relationships that carried them was the existence of wide reaching support networks. Generally, this theme represented participants' discussions of the presence and support of extended family members, pets, friends/coworkers, and individuals from community organizations. Participants talked about extended relations as supportive from two different angles: 1) being a part of their lives in general ways that they could count on, and 2) being either directly or indirectly involved in the care of aging parents with dementia. Furthermore, individuals in the wide reaching support network, oftentimes, were supportive in both ways.

Initially, participants talked about various individuals who were part of their lives. Often, they discussed individuals who were consistently around and those in which they could share their lives. For instance, Mac from Family 4 indicated that his pets were regular and beloved individuals in his life. He said, "Right and the household is [*sic*] got two dogs, a bird, and a fish. They all have our last names... They are part of the kids" (MAC.19.11-19.14, Seaman, 2014g). For Mac, his pets filled roles similar to his kids and were an integral part of his general support system.

For Stevie, Mac's sister, she told of the friends that they had met that were a regular support source. She indicated that she and Mac had met friends who shared their Filipino heritage, and with which they spent a lot of time. Stevie conveyed:

We have an extended family like a little clan. Umm there are about four other little Filipino families in the [City] area. I don't know if Mac told you... But it's like *Knots Landing*. It is like a little village, Filipino village we are in. These four families we've just been – so like it's our support system. From graduation –

from swim meets to prom nights – it’s this; we are all in proximity.
(STEVIE.4.11-4.17, Seaman, 2014h)

Stevie noted the connections she had made with four families who had become her support system. Sharing routine life happenings and landmark events, these families had become a part of her extended family. Mac also noted the relationship with the four families, and the support that he felt. He said:

Yeah with her and her husband and I met their family who lives in this area...I would get along because he asked, my brother-n-law has mostly brothers here and one sister. So we would do thirsty Thursdays at *Mulligans* (Laughter) at whatever bar. That was enough – the wings and beer. So yeah, so yeah, very close to Stevie in the last couple of years because of my situation. (MAC.30.1-30.19, Seaman, 2014g)

Mac’s “situation” that he referred to was his citizenship process that he went through when he first moved to the U.S. (MAC.29.1-29.29). During that time, he lived with Stevie, spent time with her friends, and received the support he needed while going through the citizenship process. In his account, above, he discussed how others played a part in his life, establishing himself in the U.S., and growing closer to his sister. Hence, having access to a support network outside of their immediate families was helpful to Stevie and Mac in creating a sense of community as they established themselves in their day-to-day lives. Stevie and Mac’s stories of their extended supports seem to exemplify the importance of understanding other life events and roles participants experienced in the midst of caring for their parents with dementia.

While participants discussed the supportive quality of the presence of certain individuals in their broader lives, they also noted support from those that were directly or

indirectly involved in the caregiving process of their parents with dementia. Jim and Bo from Family 2 discussed how their sister-in-law had served both instrumentally and socially supportive roles. Jim conveyed how she had been directly instrumental in finding a residential facility that would suit his father's needs. He disclosed, "before [Dad] came back [my sister-in-law] and I went to a couple of places in [Dad's town]... Yeah she was very helpful with that also... And we looked at them together" (JIM.52.17-52.22, Seaman, 2014d). Bo also relayed how his sister-in-law had been directly helpful in determining a place for his dad to live. He added, "That my [other brother's wife] and Jim pretty much did the walk thru and looked at a couple of places and this was, they felt was the best place for him in [his town]. It is a good place" (BO.15.20-15.22, Seaman, 2014c). In Jim's and Bo's opinions, their sister-in-law had been particularly helpful instrumentally in investigating care facilities, visiting them, and determining which would be the best fit for their father. Having her feedback was valuable in helping reestablish their father in a place that would meet his needs in his early stages of cognitive decline. Yet, Jim also noted how his sister-in-law had provided direct social support to him and his brothers in her information gathering and giving, as well as her validation of his concerns about his dad. He reported:

and my sister-in-law...is actually the train for that particular engine... Yeah so she's more likely to follow through and if I said like, "I want to start him on Namenda," which is a medication to maintain cognition... I'll say "call [the] Doctor and say that we want to start Namenda." This is what I am seeing because she is in town and she's been doing this with [my other brother] for a while and so she knows the doc, she knows the routines and stuff. (JIM.24.5-25.25)

Jim saw his sister-in-law's support as the go-to person to make sure his brother did the things that he needed to do to support their father. Because she had learned about the process through her instrumentally having supported their father by taking him to his doctor's appointments, in Jim's eyes, she had become a person he could rely on to understand his concerns and get the information he needed to care for his father. Thus, Jim's sister-in-law provided both instrumental and social support in direct ways.

On the other hand, Sharon from Family 5 discussed the social support she received from people at work that had helped her in an indirect way. She recounted:

I've talked to elderly people. At work, I work with a lot of elderly volunteers. So, they have, one of my coworkers had a mother... her mother had Alzheimer's. She died of complications from Alzheimer's. So, I've talked to her, but I haven't talked to anybody my age who has a parent who's going through this. And, I'm really anxious to talk to somebody. (SHARON.88.5-88.9, Seaman, 2014j)

Indirectly, Sharon's coworkers had helped her in that she was able to hear stories of caring for parents with dementia. Still, she recognized her need to connect with others of her own age that were in the process of caring for a parent with forms of cognitive decline. Yet, having had the opportunity to share with her coworkers, indirectly, gave her insight into the caregiving process for individuals with forms of dementia, thus serving a socially supportive function.

Zoey from Family 1, also experienced indirect social support from her wide reaching support network. She discussed the indirect involvement of a community organization in supporting her. She spoke of timeliness of being able to connect with people who knew about the things she was experiencing caring for her mom with

dementia. She said, “Well, certainly we’re in touch with the staff on a regular basis...and I, when I really began to see things going downhill, I talked with a social worker with the Alzheimer’s Association, and a couple of people whose parents had Alzheimer’s” (ZOEY.5.6-6.8, Seaman, 2014b). Like Sharon’s account of reaching out to coworkers to understand what she was dealing with in caring for her father, Zoey also saw a need to reach out when her mother’s cognitive health began to plunge. In her case, though, she sought out community organizations to support her in indirect ways through the dementia care process.

Still, most times participants told stories of extended support that served them in their personal day-to-day lives, as well as assisting with the care of their parents. As mentioned above, Zoey from Family 1 talked about relying on the support of community agencies to guide her in the process of caring for her mother with dementia. However, she also disclosed how her friends had gone over and above in supporting her, but also in providing direct care to her mom. She shared:

And I have a very close group of friends in [town] who have been wonderful supports... Exactly, to hold us in this space. That’s exactly correct...[Friend 1]. When I couldn’t – when I was in the hospital for a number of months – [Friend 1]... she visited my mom, who was at home at the time. She took her to her doctor’s appointments, and just, you know... Another friend, [Friend 2], made sure that if she had any needs... I mean my friends stepped in. (ZOEY.5.10-5.20)

For Zoey, the support that her friends provided was both emotionally and instrumentally supportive. When Zoey herself had been ill, her friends not only were there to help her through her illness, but also they stepped in to make sure her mom was being cared for.

By doing so, Zoey expressed how important it was that her friends not only were there to “hold the space” but also to fill in to take care of her mom’s basic needs.

Finally, Patrick from Family 3 also experienced the benefits of having day-to-day encouragement as well as support with caregiving. He discussed the integral role that his wife had in validating him and indirectly supporting the dementia caregiving process. He discussed how his wife helped him by just being there to talk with and hear him. He said, “Me and the wife you know [we talk]... Oh I would vent just to her you know she experienced umm... she was more involved than my sister-in-laws were”

(PATRICK.49.17-49.20, Seaman, 2014f). From Patrick’s account, his wife was not only his partner that he could vent to about things, but she had helped care for his mother and so had a particular understanding of the situation. In this way, she not only served a supportive role by being there to hear Patrick, she also served a supportive role in her knowledge of the caregiving situation between him, his siblings, and his mother.

Additionally, Patrick recollected how his wife had indirectly strengthened the caregiving system by creating a bridge between him and his siblings. He told of how she had been a big supporter of his sister, Erika, who had taken on the fulltime routine care of their mother with dementia. He remembered:

So as we started to learn, my wife was integral in this talking to Erika here and there about... well my sister wanted a break periodically... long story short then ...it started really building up on my sister a lot where she and my wife had a lot in doing this and telling her, “you know you need to ask for more help and demand more help from the rest of us”... You could tell she was upset and it was the pressure getting to her. Partly I think [my wife] helped give her the courage to send [the letter to us, her brothers] but Erika goes “this is becoming very burdensome for us and if things don’t change,” something like “you know I’ll drop her off at your house for three months and you will have her.” ...And that lit

up a lot of light bulbs because then we were like really appreciating my sister because we took her for granted (PATRICK.4.6-5.16)

Patrick's account represented how, in an indirect way, his wife's social support to his sister helped by balancing the roles he and his siblings were playing in the care of their mother. In addition, the support his wife provided indirectly helped to balance the contributions that the siblings were making, thereby relieving his sister of the strain that caregiving responsibilities had on her. Although, his wife did not have direct influence in how siblings would navigate the caregiving process, her outsider feedback was invaluable to helping Patrick, his sister, and his brothers balance the roles that they played in the caregiving process. Thus, in Patrick's wide reaching support network, his wife helped him in day-to-day dealings, as well as with the process of dementia care.

All in all, what emerged was a collective story of support from individuals that went beyond the immediate caregiving sibling relationships. Participants' pets, partners, in-laws, friends and coworkers, and community organizations helped to mitigate general life strain, and maintain equilibrium in the dementia care process. Wide reaching supports helped participants in their personal day-to-day experiences, but also in the specific care of their parents with dementia. However, a common thread in all the stories was how wide reaching supports provided social support. Participants highlighted the importance of having someone to listen to concerns, provide information, and "hold the space" when the need arose. Thus, individuals in participants' wide reaching support network represented another aspect of the relationships that carried individuals.

As can be seen, however, there were many different relationships that carried individuals through the years. What emerged from participants' discussions of interconnections within and outside their family of origins were themes of recapitulated roles through the years, the importance of third generations' involvement in the caregiving system, contracts or expectations of filial care, support provided amongst siblings, and the significance of wide reaching supports outside the caregiving sibling system. For participants, these relationships that carried individuals helped to balance family dynamics, maintain roles, enforce caregiving expectations, confront questions of mortality and end of life issues, open lines of communication, foster common goals, provide unity, and balance cultural expectations of care.

It is this last point about cultural expectations that leads into the next discussion. While this chapter has presented concepts focused on the individual caregiver, the individual care recipient, and understandings of a broader system of support through relationships that carry, there is still a more expansive level of the collective story that emerged in participants' narratives. On a more expansive level, ideas of culture and generational differences were revealed. Accordingly, the next section discusses the final cluster of concepts that came to light in the analysis: cultural guides.

Cultural Guides (External)

The fourth superordinate cluster that emerged was Cultural Guides (External). This cluster represented the presence of cultural or religious expectations and generational disparities between age cohorts of parents and siblings. In general, participants discussed the intersection of religion and culture in guiding family dynamics

and connecting families with the community. In addition, participants' stories had concepts of formulaic upbringings that were characteristic of the 1950s and 1960s in the U.S., parental perceptions stuck in time, and generational differences. That being said, two superordinate themes emerged from participants' stories: 1) religion and ethnicity as guides to culture, and 2) different time (generational) – relationship with parents.

Religion and ethnicity as guide to culture. The most recognizable superordinate theme to emerge under the Cultural Guides superordinate cluster was Religion and Ethnicity as a Guide to Culture. This theme was most discernible because of obvious terms relating to specific religious backgrounds and familial ethnicities that were noted in participants' narratives. Participants talked about religion and ethnicity from three different viewpoints: 1) as an approach to connecting with the community, 2) as a method of upholding traditions, and 3) as an aspect of conflict in their family histories.

Initially, families discussed their religious and cultural background and how it had helped to connect them to their communities. For example, Matthew and Zoey from Family 1 talked about how being religiously and culturally Jewish helped in building their sense of community. Matthew disclosed that while he lived out-of-town, reaching out to Jewish organizations fostered his connection with the people of the locality in which he lived. He remarked:

I didn't know anybody in [the city]. I moved there for a job. It didn't work out. So I had the experience of moving to a new city with not having anybody at all. So it worked out ok. I was able to meet people...I founded the [city's] Jewish Motorcycle Club as a way to meet people. I knew I liked motorcycling and I like motorcyclists. So I said – and I worked at a synagogue and I was around Jewish people, so I said, maybe I can combine all those things and meet people. Which actually did happen. (MATTHEW.7.19-7.25, Seaman, 2014a)

In Matthew's account, he indicated the intersection between his religion and culture and how it had helped him to reach out to a community that was new to him. Having an association with his local synagogue, and knowing that his hobby of motorcycling attracted a specific group of people, he decided to combine both interest areas into one group for Jewish motorcyclists. In founding his group, he was able to find his niche in his new community.

Matthew's sister, Zoey, also recalled how her Jewish religious and cultural background had helped her brother when he moved back home to assist in caring for their mother. She remembered:

You know what a shiva is? The Jewish mourning ritual? Well, it is seven days when the family receives guests. It's called shiva because in Hebrew, shiva is seven. Um, he recently went to the funeral of a man that he was quite close with, but he didn't know anybody else in the family. Now you would have had to drag me to get me to go. And he not only went, but he was among the last to leave that evening. And I said to him, "what were you talking about?" And he said, "Oh I met Marilyn who did this, and I met..." And I thought "you're a crazy person." And he's like "flat out crazy person." He's curious. He likes people.
(ZOEY.40.24-40.30, Seaman, 2014b)

Zoey described how the Jewish tradition of shiva, or the seven-day mourning ritual, had brought Matthew together with many people who he had not known. However, the experience of participating in shiva for the passing of his friend gave him the opportunity to mourn his friend and create new relationships – especially in a time of grief and reestablishing himself in his hometown. Thus, Matthew's religion and cultural background worked to connect him with his community.

However, one of the most frequently discussed manners in which religion and culture emerged in participants' stories was in their examples of upholding cultural traditions. Bo from Family 2 illustrated this point. He talked about upholding his cultural tradition by using Jewish philosophy to guide him in deciding how to address a conflict with one of his brothers. He recalled:

Well it was interesting I mean... I kept asking him about three years in a row on Rosh Hashanah and Yom Kippur I would ask him for forgiveness you know... And he just was really cantankerous and really just holding that grudge tightly you know. It must have really hurt him badly... But it is interesting so I asked him for forgiveness for about three years in a row and then I – there is this old Jewish – the thing is you can only ask somebody so many times, and if you ask them directly and they don't forgive you – you only have to do it twice really umm... and I mean according to Jewish law I believe two or three times, and if they don't forgive you then it is their problem basically... I tried to just deal with it all and let it go and just be who I need to be and deal with what I need to deal with. If he wanted to hold onto it then it was sort of his issue and that's sort of where I ended up with it. (BO.27.2-28.15, Seaman, 2014c)

In Bo's experience, the religious and cultural codes of Judaism delineated certain conventions of asking for forgiveness. This code guided him in how to approach the consternation between him and his brother. Although, in Bo's experience his brother did not accept his forgiveness, going through the process dictated by Jewish law helped to provide a mode to make contact with his brother and also uphold the standards of his culture.

Whereas in the two examples above participants described positive ways that culture and religion helped to guide them in connecting with their communities and families, culture and religion also created conflict in some participants' stories. For

instance, Erika from Family 3 discussed how her parent's ethnic and religious background impacted their expectations for her. She described:

And the other thing was my parents had this... because I was the only girl you know. They had this vision that the person I would marry would be from Parma. He would be Polish. They would know his family... It would be just the perfect picture. So he's from out-of-town. His parents are divorced. I mean he is Catholic though but that wasn't enough. That didn't weigh anything... No, no. The only little thing was that he went to church. But so this was the first time in life that I had some conflict with my parents. (ERIKA.28.27-29.3, Seaman, 2014e)

In Erika's experience, her parents had firm expectations that were meant to guide who she would marry. In the example above, the expectation was not only that her future partner be Polish and a practicing Catholic, but also that he be from their neighborhood. Unfortunately, as Erika reported, her then future-husband did not quite meet their expectations, and thus created conflict between Erika and her parents – conflict that would last well into present day. Erika explained, “so in [my mom's] mind, she has never let go of her disappointment... 45 years ago” (ERIKA.41.33-41.34). Therefore in Family 3, expectations dictated by religion and ethnic culture elicited conflict between parents and children when expectations were not met.

Accordingly, religion and ethnicity acted as guides to participants' family cultures. In their stories emerged positive representations of religion and ethnicity helping families to connect externally in their communities, but also internally among their siblings. However, what also surfaced was a more negative presentation of religious and cultural guides creating discord between parents and their adult children. Thus, when family members were in concordance with the cultural guides, harmony seemed to be

achieved, and when their viewpoints were divergent, conflict occurred. Still, perhaps the conflict was evidence not only of differing perspectives, but rather incompatible ideals between generations. In the next section, generational differences will be discussed as they relate to the last superordinate theme to be discussed in this study: Different Time (Generational) – Relationship with Parents.

Different time (generational) – relationship with parents. The final superordinate theme to be presented in this chapter is Different Time (Generational) – Relationship with Parents. Basically, this theme represented participants' accounts of traditional roles their parents played while participants were growing up in time periods of the 1950's and 1960's. Additionally, it represented how their parents had maintained those roles and ideals as they made sense of things in their present lives. What emerged in participants' accounts of the superordinate theme, different time, were discussions of an "idyllic" (MATTHEW.17.10, Seaman, 2014a) or "different" (BO.43.19, Seaman, 2014c) era that centered on three main ideas: 1) traditional roles representative of generational ideals, 2) parental perceptions stuck in time, and 3) generation differences.

Participants talked about the period in which they grew up as a different time or a different era. The difference was evidenced in participants' discussions of idealized childhoods, as well as the traditional roles that they and their parents played in their early years as a family. For example, Jim from Family 2 described the halcyon days of his youth. He remembered:

Well, when we were growing up we did a lot of stuff together. We always did stuff together... Yeah, and although on Sundays my mom got the day off and my dad would take us out somewhere and we would do something together... Yeah,

yeah, we spent time together and we had meals together... Because it was the 60s, 50s - 60s... That was a pretty good time. (JIM.41.15-42.21, Seaman, 2014d)

Jim recalled the good times that he spent with his family in his early years. In particular, he noted that he grew up during the 1950's and 1960's, and thereby connected his idealized childhood to the specific generation of those who grew up during that time period. Additionally, he remarked about how his mom was given the "day off" from her regular duties of caring for the family – a role that he remembered women primarily filling during the 1950's and 1960's. He added:

She did not [work]. My dad owned a jewelry store; my grandfather owned a jewelry store...she would do things adjunctively with the business. For example, every year they would have a table-setting contest so they would like different organization, for charity, would set and they would do that in the stores. She did a lot of secretarial stuff; she could type a million words a minute and she ran the house like women did back in the late 50's and 60's. (JIM.33.19-33.25)

Jim recalled the specific gendered roles that his mother took on – roles that were customary for women to fill in the 1950's and 1960's. In his perspective, elements of his ideal upbringing included his mother staying home to care for the house and the family, his father being available on the weekends for daytime adventures, the family sitting down at the table to eat together, and just spending time together. For Jim, it was how they did it in an upbringing where traditional roles were idealized.

Patrick from Family 3 also recalled an idyllic time in his early years with his family. He remembered how his family had a cottage they would go to in the summers. He disclosed:

Oh yeah when I was growing up we had a cottage [out of the city] you know [mom] would spend the whole summers out there with us... [Dad] would take us out there – he would still work. He would just commute from there. He would sometimes stay over here on the week and stay out there on the weekends... when we were kids [mom] didn't have a car... We had good times out there. (PATRICK.53.20-54.3, Seaman, 2014f)

Part of Patrick's early years was spending joyful times at his family's summer cottage.

Similar to Jim's account, Patrick recollected his mom spending her time with the children, while his dad was available on the weekends after he was done with work. He went on to describe the fun they had at the summer cottage in the idealized time period of the late 1950's and 1960's. He recalled:

My dad built this cottage when I was born late 50's so it was like a little summer community place to get away. Great fishing... Gbrother and Erika were lifeguards there, a lot of fishing, and there were all kinds of dancing at community hall... My dad was involved. It was a blast growing up there, resort type of thing. We had a great, growing up - it was a blast. (PATRICK.54.5-54.12)

Again, similar to Jim's experience, Patrick also noted his exemplary upbringing in the late 1950's. For him, this was a blissful time because of the fun things he was able to do, having his older siblings (Gbrother and Erika) there to share it, having his mother regularly there for him and his siblings, and having his father involved on the weekends. Like Jim, Patrick described the traditional roles of his parents that contributed to the sharing and involvement that he felt in his early years. For both Jim and Patrick, their idealized childhoods were connected to a generational time period where traditional roles supported familial functioning.

Although participants looked fondly on their upbringings, they also told stories of how their parents' mindsets seemed to be based on standards of their early years. For example, Jim from Family 2 commented about his father's business sense that seemed to be based on an earlier time. He explained:

So yesterday, [my dad] goes "I don't think I am going to subscribe to the Wall Street Journal anymore."... He said, "well he have to cancel the Wall Street Journal." I said because it was 7 o'clock at night. I said, 'I'll call them now.'" [then he said] "We'll call them in the morning." I said, "no, I'm calling them now." It's his understanding about how the way it works is correct for his times, but it's out of sync for this time. (JIM.28.25-29.16, Seaman, 2014d)

In this account, Jim wanted to immediately address the canceling of the paper for his dad. However, because of the time of day being 7 o'clock at night – and traditionally after business hours of 9AM – 5PM – his father wanted to wait until the morning. In Jim's viewpoint, his dad's sense to wait until morning to call was an artifact of another era and out of sync with present day business practices. Thus, a mindset created at a different time was in a sense keeping his father's perceptions stuck in time, and in conflict with current conventions.

Erika from Family 3 also discussed her mother's perception of herself as stuck in a different time. She talked about how her mother had been dependent on her father for many things through the years, so much that she never learned to drive. She disclosed:

...my dad was chauvinistic to a degree that he didn't think she needed to drive. If she needed anything, he would see that she got it... So when it was grocery shopping - had to happen in the morning when he came home from work - he would take her... She... if you can imagine this. My mother was never in a grocery store by herself. And I could not fathom that. And I ...Right and when I'd say to her, "mom why don't you... why don't you learn to drive?" [and she

would say] “Oh your dad doesn’t want me to learn how to drive”... So once my father died... that’s when I decided my mother has to learn to drive...And oh maybe she was 71 when my dad died and 73 when I taught her to drive...So I mean it took so much prodding for me to have her pass a written temp exam and then actually getting her behind the wheel... Yeah and as I told you before. Zero self-esteem. “I’m not smart enough to drive. I can’t do this. I don’t have good judgment.” I go “mom, you do. You do.” (ERIKA.10.17-11.23, Seaman, 2014e)

In Erika’s account, she described her mother’s mindset about her own efficacy to drive – a perception that had developed when she was first married to her husband. Erika’s father seemed to take her mother’s duty as a homemaker to the extreme degree in that he believed her place was literally only in the home, unless she was with him. As Erika described her mom having low self-esteem, one can imagine that it would be easy for her mom to go along with her father’s point of view. Unfortunately, as Erika noted, her mother’s mindset of her capability to drive along with her own self-regard had not changed even after her father’s death. Even though she eventually learned to drive, it was still something that she did not feel confident about doing for herself. Therefore, Erika’s mother continued to use perceptions of self that were stuck in a past time.

Interestingly, Erika’s story also featured apparent generational differences between her mom and her. That her mom never learned to drive and had never been in a grocery store by herself (ERIKA.10.25-10.26) was something Erika could not fathom. In a sense, the more independent expectations that Erika held for her mother may have been based on what was customary for Erika’s generation, while her mother’s expectations were based on an earlier time. These generational differences were revealed in other participants’ stories as well.

For instance, Bo from Family 2 discussed the generational differences related to his father's expectations of his children's eventual vocation. He recounted:

I was in, my father was in the jewelry business as was his father and his father put my father into the jewelry business when he got out of the war, World War II. He said I have a business for you to run even though he wanted to be an engineer... so my father being the creative type, he made a real go of it but it certainly wouldn't have been his first choice of what to do but he did a great job... And it was a different time... It was very much a different time and that time is gone so then my brother RBrother went into that business with my father probably in the 60's... my parents were big pushers to get the kids in the business... (BO.18.2-18.26, Seaman, 2014c)

Bo conveyed a story of the jewelry business legacy that had been handed down in the family since his grandfather's original business before World War II. In Bo's account, his father was expected to take his place beside his grandfather in the jewelry business, even though he had planned to be an engineer. Additionally, he reported how his brother followed suit. However, he also added about his own ambivalence about taking on the jewelry business. He revealed:

Oh okay, so umm... so then I went into the business well I was, I graduated from college with a degree in experimental media, in film... "What do you do with that? How are you going to earn a living with that?" So my parents of course are pushing that, oh yeah son's they're in the business... Oh yeah it just went to hell in a handbag because they, my parents were trying to get out of the business and force certain things and then family dynamics and politics and business and not well thought out. (BO.19.17-21.9)

Bo recalled his hesitancy to get into the family business, especially with his interest areas in a divergent field. However, with the pressure from his parents and the family legacy to uphold he took his place with his father and brother. The eventual downfall of the

business, however, may point to differences in generational expectations. Even Bo noted in his earlier statement that, “it was a different time” (BO.18.15). Perhaps the time period of the 1950’s and 1960’s was one where there were more circumscribed roles for mothers, fathers, and children – roles that were taken seriously, and where there were clear boundaries for what individuals did in those roles. Contrasting those rigid role expectations with the roles that mothers, fathers, and children play in today’s fast changing world, it is easy to see how disparities can arise in expectations between different generations.

Yet, generational differences were not only present between parents and children, but also between siblings. In Family 5, Kevin described variability in relationships and experiences based on the wide range of age differences in his 10-person sibling group. He disclosed:

Yeah. Catholic. You marry for life, and for good or for bad, for better or for worse. And, I think with 10 kids there was a lot of worse and not a whole lot of good ...it’s a miracle. And, you know, that’s why, if you imagine, 10 kids, having 10 kids over the course of 20 years. Each of our experiences are going to be different because the financial situation was different. There wasn’t a whole lot for any of us. But, the stresses on us individually were all really different... Um, and our experiences are all distinctly different. (KEVIN.12.13-12.25, Seaman, 2014i)

Generationally speaking, Kevin’s parents had children during a time when it was customary to have large families, especially if one was part of a religiously Catholic family (Blake, 1966). Yet in our modern world, having 10 children is not as usual as it once was (Jiang & O’Neill, 2007). In addition, Kevin noted the forces impacting the disparities between generations of his siblings. He observed that at any given point

siblings could experience a different financial situation dependent on who was part of the household, encounter various stressors dependent on the level of resources and availability of certain family members, and have completely different experiences simply because of the great span of 20 years that separated siblings. Thus, generation differences had their own sorts of impact on the relationships between siblings, just as they had on the relationships between parents and their children.

Bringing it all together, participants' stories revealed patterns of a different time. They told stories of ideal pasts that were characteristic of carefully organized families where parents took on the prescribed roles and children followed suit. Additionally, participants' disclosed experiences of seeing conflict of their idealized upbringings in out-dated standards that their parents had maintained through the years, as well as in the generational differences in expectations of how family members would conduct themselves. From all these points of view what was clear was that looking back at participants' lives in comparison to their current realities as caregivers to their parents with dementia, it was certainly a different time.

Yet, more than it being a different time, participants were impacted by religion and cultural traditions of their families. The superordinate themes of Religion and Ethnicity as Guide to Culture and Different Time (Generational) – Relationship with Parents went hand-in-hand in considering participants' experiences – as well as their perceptions of their experiences. Together, they acted as cultural guides for participants' past and present – dictating at larger system level how to interpret and act on events in life. Although the superordinate themes under the Cultural Guides superordinate cluster

were not always directly related to adult siblings' caregiving to their parents with dementia, it is not challenging to see how this cluster of themes could influence the superordinate themes that made up the superordinate clusters of the Individual Caregiver (Internal), Individual Care Recipient (Parent with Dementia – Internal), and Relationships that Carry Individuals (External).

Process Themes of the Interviews

During the semi-structured interviews, some participants provided feedback about the process of the interview and being a part of the project. Generally, participants believed that the interview and discussion of caregiving and family dynamics were validating and timely. In addition, the researcher reported on experiences in meeting with participants. Process themes are summarized in Appendix J.

Participants commented about how validated they felt in telling their stories. For instance, Jim from Family 2 talked about how it was satisfying to reflect on what he and his siblings had done in the caregiving process for their father. He commented, "I mean it's nice, sort of some level self-satisfying to be able to sit and talk about this and go "yeah, yeah, we do that, and this is what we do" (JIM.89.4-89.6, Seaman, 2014d). For Jim, talking about his experience as a caregiving sibling was validating in that it was kind of a record of what he and his siblings had done together to help their father.

Also, Stevie from Family 4 discussed the power she felt in being able to talk about what she was experiencing since there were still so many unknowns for her and her siblings in the caregiving of their mother. She said:

Well, I think it is positive that there is a space created with someone who is not a relative, an outsider that can just confirm or agree or be willing to listen provide the space for us to impart all the things we know and don't know and just you know... I think there is power in the questions when you ask things I didn't really think about; yeah there is power in that. Holding space and giving me resources and just a general, not restlessness but I guess expectant attitude toward what's next, where do we go from here? Can someone really navigate us through when we go to deeper waters? I am just really scared about that. (STEVIE.43.33-43.37, Seaman, 2014h)

For Stevie, having an outsider hear her experience and offer resources (i.e., resource packet, See Appendix D) was validating. In addition, she found power in being able to think about new questions that she had not considered before. Still, it seemed to arouse more questions about the caregiving process.

Additionally, participants discussed how timely the interview was for what they were dealing with in the dementia care process for their parents. For example, Sharon from Family 5 reported:

And it's so ironic that your mom contacted me, because I have really just been pushing – the back of my mind creeping forward about going to find a support group. For someone else to talk to. Not my sisters and not my mom. Because I get their view all of the time. It's like in my head and I want someone else's view. So, I think this was really perfect timing. It's good to talk to someone else. (SHARON.90.10-90.14, Seaman, 2014j)

Sharon also expressed her satisfaction in having someone to talk with outside of her family unit. In a way, it provided her support she needed to process what she had experienced in caregiving for her father with dementia.

Some participants hoped that they had given the right kind of information for understanding the phenomena of caregiving siblings to parents with dementia. For

instance, Patrick from Family 3 said, “Hopefully I gave you some of the right type of information that you can use” (PATRICK.60.21, Seaman, 2014f). Matthew from Family 1 also expressed his concern that he talked about the things that would be beneficial in understanding the caregiving experience with his sibling. He conveyed:

Well, I’m curious what you’re going to take from it. In part, it didn’t focus to the extent that I had imagined on the experience of being a sibling taking care of a cognitively impaired parent – as directly and as concretely as I thought maybe would be explored... I thought there were going to be more questions along the lines of how did we share, sort of some of those things in the demographic [questionnaire], sort of perusing some of those things...(MATTHEW.32.23-33.7, Seaman, 2014a)

Possibly the questions that both Patrick and Matthew had about the value of their information to the study was based on their expectations of talking only about the specific caregiving tasks in which siblings engaged in the care of their parents with dementia. Although deciphering caregiving responsibilities was a part of the study, a bigger portion was understanding the relationships and support experienced in caregiving systems of siblings, as well as their perceptions of what their parents with dementia were going through in the caregiving process.

Furthermore, the researcher noted certain process experiences. The most notable experience was the development of relationships with each participant. Almost all the interviews were conducted in the homes of the participants, with the exception of the last three interviews – they were conducted in private areas of public venues (i.e., participant’s workplace after business hours, the researcher’s workplace office, and a coffee shop). In cases where the interview was in participants’ homes, participants were

hospitable and frequently showed the interviewer pictures of their family members, introduced their family pets, and offered comforting libations. In cases where interviews were held in public venues, participants also offered anecdotal stories of their children and family members. Nonetheless, each participant displayed warmth and openness to the conversation. They engaged the interviewer with personal questions such as how the topic of adult siblings caring for aging parents with dementia came about and how close was I with my siblings. The interviewer responded openly and honestly about personal experiences on the research topic. It seemed that the conversation before the interview began was valuable in helping participants feel trust, safety, and comfort in revealing their personal experiences.

However, within the interview process, certain points of conflict arose. The researcher noted personal emotions of empathy, sadness, and frustration at hearing some of the stories that participants told. Particularly, in Family 3, Erika's and Patrick's stories revealed very much conflict between siblings in the caregiving process. Erika talked about the rivalries between her brothers and about the lack of support she felt at times (ERIKA.17.31-17.33, ERIKA.20.20, Seaman, 2014e). Additionally, Patrick discussed the rivalries with his brothers and his beliefs about the imbalance in how much and what his siblings were doing to care for their mother (PATRICK.4.15-4.18, PATRICK.12.1-12.29, Seaman, 2014f). Furthermore, both Erika and Patrick discussed the alliance they had formed, in part in their discontent with one of their brother's lack of contribution (ERIKA.27.26-27.27; PATRICK.4.23-4.32). Although their stories revealed similar themes, what was most challenging in hearing their accounts was the incongruity in their

perceptions of which siblings were doing what, and how siblings were contributing. Indeed, there were times when Erika would report that one of her siblings helped in a certain way, and her brother Patrick would have a different understanding of how that sibling helped. Being the researcher working to maintain the confidentiality of the interviews, but knowing at least two sides of the story, it was frustrating to not be able to offer clarification about certain points. Additionally, it was frustrating to hear the perspectives of the participants on their siblings, but not be able to hear the points of view of their siblings – there was a sense that if participants' other siblings had a chance to tell their side of things, the collective story would significantly change.

Even with the aforementioned challenges in the process, there was much gained, as has been noted. Participants felt validated in disclosing their experiences and expressed the timeliness of being able to talk about the caregiving process with an outsider. Moreover, the researcher experienced hospitality and requests to disclose personal experiences about the research topic. All of the above seemed to help participants feel assured and secure in telling their stories.

Member Checks

The researcher contacted participants to follow up with them about their participation in the study and to get their feedback on their cleaned transcriptions, as well as their questions or comments on the aggregate findings of the research. The researcher sent each participant a personalized follow up email with an attachment of their respective transcript and a table of the 18 themes that were found in the data analysis. Six of the ten participants responded to the emails. For the most part, participants reported

that they had things going on that prevented them from reading the materials thoroughly, but that they would send feedback if it came up. However, two participants had more detailed comments. One participant expressed amazement at the length of the transcription, and after examining the aggregated themes she reported she had more questions. Another participant conveyed her surprise at how she said things, particularly noting idiosyncrasies in her expressiveness. However, she also reported that she was happy that she could help and relieved that her brother could be a part of the process too.

Summary

This chapter reported results of interviews with 10 individual siblings (five sibling pairs) who were caring for a parent with dementia in the Midwestern region of the U.S. Data were collected from demographic questionnaires and semi-structured interviews. Results from the demographic questionnaires were presented on caregiving activities of participants and their perceptions of their siblings' involvement. Additionally, results of thematic analyses of the interviews were reported, specifically with regard to four superordinate clusters and 18 superordinate themes that emerged in the study.

Generally, the demographic questionnaires revealed basic information on how participants and their siblings contributed, how often they did so, and how participants' perceived connections and support from siblings. In particular, participants reported contributing more hours of dementia care than their siblings, though they perceived that they and their siblings were doing similar tasks in the caregiving process. In addition, participants reported that social support received from siblings was varied and dependent on their relationships with them. Yet, all participants indicated some form of support.

Finally, participants described their sibling connections in mostly positive terms, including *good*, *strong*, *interconnected*, and *primary support*. However, some siblings appraised their relationships in more negative terms such as *bad*, *disconnected*, *zero respect*, and *less than*. Basic information on the demographic form revealed that even though participants reported that they contributed more hours than their siblings, they believed that they were connected to at least some of their siblings and that their siblings were supportive.

Still, the information gleaned from participants' interviews shed more qualitative light on their experiences in the dementia care process with their siblings and their parents. Basically, what emerged in participants stories was a four-tiered system of experience made up of four superordinate clusters: 1) Individual Caregiver (Internal), 2) Individual Care Recipient (Parent with Dementia – Internal), 3) Relationships that Carry Individuals (External), and 4) Cultural Guides (External). Within this four-tiered system of superordinate clusters, 18 superordinate themes were held. In the first superordinate cluster, Individual Caregiver (Internal), seven superordinate themes emerged related to caregivers judgments of themselves and their siblings. Participants believed that their and their siblings' caregiving approaches were based on personality differences that had been in part formed based on relationships between family members. They also believed that caregiving approaches that they and their siblings took on were related to having active lives; competing obligations of spouses, children, strained relationships, and caring for in-laws; burdens placed on them by parent's behavior and lack of appreciation, as well as recognizing that their siblings were taking on too much in caregiving; bonds and alliances

being created over and beyond the caregiving experience; initiative to support parents with dementia, but also their siblings; and professional roles or self-education to provide to the caregiving process.

In the second superordinate cluster, Individual Care Recipient (Parent with Dementia – Internal) four superordinate themes emerged related to participants' perceptions of their parents' behaviors and identities related to their cognitive decline. Additionally, they discussed triggers to the dementia developing, and the pros and cons to formal care involvement. In general, participants believed dementia formed in their parents based on certain triggers such as previous illnesses or conditions, lifestyle factors, death of spouse, and other loss and bereavement. Another type of trigger seemed to be a lack of identity or niche in the family. Specifically, participants reported that when parents' independence was threatened or when they were left with no determined role to fall back on, their parents seemed to develop forms of cognitive decline. Also, participants discussed their experience of role reversal in that caring for their parents was like caring for a child. Furthermore, although some participants discussed positive features of the formal care process, in most stories what emerged were formal care problems related to medication management mistakes, discrepancies in diagnosis, inconsistencies in caregiving procedures, and staff turnover. Most disheartening to participants were the difficulties that applying for and utilizing Medicare/Medicaid benefits presented.

The third superordinate cluster, Relationships that Carry Individuals (External) represented a broader order of understanding participants' experiences and perceptions in

caregiving for a parent with dementia. Five superordinate themes emerged basically representing the overarching caregiving system-level contributions that roles through years, third generations, filial expectations, sibling support in caregiving, and wide reaching supports played. Basically, participants believed that their siblings, their children (or the grandchildren to participants' parents), and their extended family members, pets, friends, and community centers formed an expansive network of support. Most notable, however, was how roles and relationships that were created in families of origin were maintained into adulthood, whether they were harmonious or conflicted. People stayed the same over time.

The final superordinate cluster, Cultural Guides (External) represented an even broader degree of awareness of the systems impacting participants' experiences and perceptions of the dementia care process. In this superordinate cluster, two superordinate themes emerged representing global insights of the context in which participants experienced and perceived dementia caregiving processes: one relating to participants' stories of religion and ethnicity as it guided them in their relationships with their family members and other system members, and the other relating to a different time with parents and generation discrepancies. What was found in participants' narratives was evidence of community connections, valued traditions, and points of conflict connected with participants' religious values and ethnic customs. In addition, what also became visible were idealized notions of upbringing – primarily based in traditional gender roles; perceptions of parents' mindsets stuck in the standards of early generations; and generational differences in expectations that influenced conflict between family members

regarding self-determination, vocational aspirations, availability of financial resources, and influences of different siblings.

The next chapter will further discuss the findings of this study as they connect with past research, and will outline the implications for adult sibling caregivers – specifically those caring for parents with forms of cognitive decline and dementia. In addition, implications for counselors and other professionals that work with this population will be noted. Furthermore, limitations of this study will be addressed, and future recommendations will conclude this research.

CHAPTER V

DISCUSSION

The purpose of this dissertation study was to explore the perceptions and experiences of sibling connection and social support between caregiving siblings to aging parents with dementia. Researchers have found that oftentimes it is adult children who provide the majority of care (NAC et al., 2011). Additionally, researchers have revealed that family caregivers caring for loved ones with dementia are more likely to report higher stress and burden than other caregivers because of the specific challenges of providing dementia care and coping with its intensified symptoms (Alzheimer's Association, 2011a; Bertrand et al., 2006). Furthermore, they have found that family caregivers feel a lack of social support in the caregiving process (Adams, 2006; Dilworth-Anderson et al., 2002). Specifically, Adams (2006) found that family caregivers felt disconnected from social support and were reluctant to help because of strong determination to maintain familial interconnections and communications as they always were.

Commonly, ways in which dementia caregiving concerns have been addressed are through the provision of formal care services focused on Activities of Daily Living (ADL) and medical services for dementia care recipients (Alzheimer's Association, 2011a; DARTS, 2012; Eldercare Partners, 2013; MetLife, 2011; U.S. National Library of Medicine, 2012). Additionally, focus has been placed on primary caregivers and their

relationship to care recipients (Altercare of Ohio, 2012; DARTS, 2012; Matthews & Rosner, 1998; Spectrum Retirement Communities, 2012). Furthermore, service providers have used network models to assist families that do not account for interconnections and communications that influence dementia caregiving between family caregivers – notably adult sibling caregivers (Sims-Gould & Matthews, 2007). The aforementioned routine approaches are limited by focusing too much on medical standards and instrumental tasks in maintaining care recipient health and supporting families; they overly emphasize the roles of individuals who label themselves as primary caregivers, and do not give consideration for the various ways all siblings are involved in the dementia care system; and they lack a theoretical model that supports various contextual factors, which influence the system of care for aging parents with dementia. Thus, there is a lack of understanding of the interconnections and supports of family members, namely adult siblings. Moreover, there is an insufficiency of information on family dementia care from the caregiving sibling system level.

The researcher of this study wondered about the gaps in the current literature and models of helping adult siblings who care for aging parents with dementia. With the prevalence of adult children caring for their parents, and increased risk of stress and burden for those who care for loved ones with dementia, the researcher questioned whether there were other contextual and systemic phenomena that could bring clarity to the complicated processes of familial dementia care. Adult siblings, counselors, healthcare professionals, counselor educators, and dementia care researchers could stand to benefit from learning the important issues that families face when collaborating in

dementia care by understanding the important patterns of connection between caregiving siblings that may inform best practices and therapeutic interventions for families.

To explore the phenomena in families caring for aging parents with dementia, phenomenological semi-structured interviews were conducted with five families, including two siblings from each family. A total of 10 adult siblings completed demographic questionnaires and independent 120-minute interviews. Participants were sisters and brothers who were currently caring for a parent with a form of dementia. A discussion of the results and how they impact the knowledge about familial dementia caregivers is presented below.

Discussion of Results

Results of this study confirm the importance of examining dementia concerns and providing assistance and resources from a systemic and contextual paradigm to adult siblings who are caregiving for a parent with dementia, rather than working from a primary caregiver network model. Additionally, providing different levels of social support seemed to be most important in balancing the dementia caregiving system rather than medical and instrumental tasks taking the forefront. Moreover, cultural guides related to ethnicity, religion, and generational differences proved to be important to helping caregivers in dealing with and understanding their parents' cognitive decline. These findings are important because they underline the need to help caregivers by fostering or rebuilding collaborative connections, promoting support from within caregiving systems, and building harmonious caregiving systems based on cultural

principles in caregivers' lives. To best address the discoveries of this inquiry, attention is now turned to the research questions.

Addressing the Research Questions

Three research questions framed this study. They were created directly to address the gaps in the literature related to interconnection of caregiving siblings, social support experienced and perceived in the dementia care process, and the involvement of multiple adult siblings in the system of dementia care. Discussion of the research questions is presented below.

RQ 1: What phenomena emerge that clarify caregiving siblings' perceptions and experiences of sibling connection in dementia care? Collaborative caregiving and maintenance of balanced sibling roles were most important to caregivers in the experience of sibling connection. Basically, these elements of sibling connection helped caregivers feel emotional closeness in tough situations of dementia care, and allowed siblings to build off of the roles that they had played through the years to help them balance their own lives and caregiving responsibilities. This finding was particularly interesting because past research has emphasized the significance of family expectations, sibling factors of proximity, family organization, and competing obligation, and caregiving styles of involvement in determining contributions and collaboration (Matthews, 1995; Matthews & Rosner, 1988; Russo, 2010a). However, these aspects did not seem to explain the experience of sibling connection. Rather, having a team-like quality in setting expectations of caregiving promoted emotional and mental closeness

and having a history of balanced roles in the family of origin gave meaning to the connection between siblings.

Emotional and mental closeness to siblings. One of the keys to sibling connection was coming together as a team to set expectations about caregiving. This helped participants to feel mutually connected and motivated to regularly visit and talk with siblings, help each other, provide insight, listen, share information, take time and care, create a safe place to converse, and possess a team-like quality. Past literature on sibling connections also confirmed the importance of the experiences participants had in their relationships with their siblings. Researchers have found that sibling relationships can be places for nurturance, guidance, and social connection (Lewis, 2005; Namayslowska & Siewierska, 2010). Cicirelli (1995) found that as siblings got older they had increased feelings of closeness, companionship, and support – even in cases where contact was reduced. Results from this study validated past research in that participants reported they felt nurturance, guidance, and connection with their siblings.

Nonetheless, past research has found that various circumstances can play a part in the degree of connection that siblings have in dementia caregiving. Researchers have found that family expectations of filial care that are gendered and based on aging parents' generational ideals can bring certain siblings together, and isolate others from connection (Matthews, 1995; Matthews & Rosner, 1988; Russo, 2010a). What emerged in this study, however, was that adult siblings, acting together, had generated their own expectations of filial care, regardless of parental ideals of how adult children contributed to filial care. Siblings' working together to generate expectations seemed to lay the groundwork for

connection and closeness in the sibling relationship. This pattern of working together as a team, also has been found in past research. Ingersoll-Dayton et al. (2003) termed the process of harmonious and fair caregiving as *collaborative caregiving*. They found that caregivers worked together to negotiate the sharing of caregiving tasks, to redefine the caregiving system, and make decisions as a team. Caregivers in the current study connected in similar ways with each other. What was key to connection was coming together as a team to set their own expectations of roles and responsibilities in dementia caregiving.

Roles played in the family of origin. Another key aspect of sibling connection was understanding the history of sibling connection and then either fostering the maintenance of sibling connection, or rebuilding the relationship by diffusing misunderstandings. For instance, one sister recalled how her brother “ran interference” for her, even in his role as the “golden child” in the family (ZOEY.8.17-8.24; Seaman, 2014b). In her family of origin, the balance that was contributed by her brother’s trust, care, and loyalty to protect her from her parents’ criticism created harmony and connection in the sibling relationship – connection that had been maintained through life’s ups and downs, such as marriage, moving out-of-state, children, divorce, illness, and caregiving for their mother. Thus, the roles these participants played growing up in their sibling relationship that contributed to the connection they felt through the years and in the dementia caregiving process. This history of roles was discussed in previous literature. Researchers found that ways in which siblings and parents connected in adulthood were frequently indicative of pre-existing approaches to interacting. Schulman

(1999) found that family of origin roles had a way of influencing characteristics that siblings took on as independent adults. In the above example of the importance of family roles, the sister represented a positive and cohesive case of sibling connection. Some participants, however, had narratives of rivalry and disconnection in the roles they played in their family of origin.

Other participants told stories of conflict in sibling connection that had persisted through the years. In particular, what seemed to provide meaning to the conflict between siblings was that often their roles were undifferentiated, and those undifferentiated roles led to conflicted relationships, creating a history of unbalanced roles that persisted into the dementia caregiving system. For instance, one brother described the pugnacious connection that he and his brother had as kids, which had persisted into their adult lives. He spoke of how he and his brother never got along, and that he was often lumped with his middle brother in identity. His sister corroborated his perceptions of being identified with the general recognition as one of the “boys.” She remembered:

And whenever the boys would come home, they would just give a grunt for an answer you know. Or all they might say is “what’s for dinner”... Because [mother] enjoyed me as a daughter much more than sons. They just weren’t the same thing. I mean she just couldn’t compare having a daughter and sons. They were like apples and oranges. (ERIKA.32.14-32.18, Seaman, 2014e)

This sister added more insight to reasons behind the rivalry between her brothers. She said:

So like when I was 18 and leaving, they were 14 and 12. So they went through high school and middle school without me in the picture. So I really wasn’t aware that they had these little things going on. So, and then Patrick became a policeman

okay. And KBrother thought that Patrick became a policeman because he liked the power of the role... And [Patrick] would never talk about his work. Only a couple of times recently has he talked about his work. KBrother just had the wrong perception of this. The wrong perception. (ERIKA.25.27-26.10)

The importance of this kind of conflict in roles is twofold: 1) being undifferentiated in roles created conflict between siblings, and 2) hostile roles had been maintained through the years to create disconnect in adult roles as caregivers to their parents with dementia. First, theorists such as Alfred Adler and Murray Bowen have discussed the importance of differentiating in families, and that by not differentiating individuals can feel a disengaged sense of social interest and disoriented sense of authentic self (Sharf, 2004; Wedding & Corsini, 2013). In the above example, brothers were at odds because of misperceptions about past events and experiences. Kahn and Bank (1981) refer to misperceptions of siblings that are stuck in the past as frozen misunderstandings. They are distorted images of earlier sibling relationships with siblings. Kahn and Bank have found that frozen misunderstandings between siblings maintain past hurts that continue to influence siblings, even in novel circumstances that call for refreshed approaches to handling them. In the current study, although many of the participants revealed stories of positive connections between siblings, it appeared that some siblings functioned in their caregiver roles from a system that was stuck in the past and hindered the connection between siblings in the dementia caregiving process.

Key to sibling connection was understanding the history of roles and then fostering the maintenance of positive connections or diffusing negative connections and rebuilding them to be more functional. Regardless of the change in circumstances,

participants talked about how the roles they and their siblings played in their families of origin were the very roles they played in the caregiving process. On the closely connected end of the sibling connection spectrum, sisters and brothers discussed how they had learned to respectfully communicate between siblings and take care of each other while growing up. This close connection persisted and assisted them in the dementia caregiving process. On the disparately distant end of the spectrum, sisters and brothers disclosed patterns of conflict and comparison that developed in childhood and endured into the caregiving process.

In summary, having a team-like quality in setting expectations of caregiving promoted emotional and mental closeness, and understanding and working with the history of roles in the family of origin gave meaning to the connections between siblings. These points have been validated by past research that found, a) working in a team like quality in the sibling dementia caregiving group helped to bring siblings more connected (Ingersoll-Dayton et al., 2003; Schulman, 1999), and b) roles that siblings played in the family of origin were maintained over time, and either contributed positively or negatively to sibling connection in dementia caregiving (Kahn & Bank, 1981).

RQ 2: What phenomena emerge that clarify caregiving siblings' perceptions and experiences of social support in dementia care? Essential to caregiving siblings' perceptions and experiences of social support was being able to receive emotional and mental validation and compassion from siblings and other members of the family system. In this study, it was shown that over and beyond the provision of material goods and services, having different types of social support by fellow siblings was crucial to helping

caregivers in the dementia caregiving system. Additionally, these types of social support came from sources within family systems and stretched wide to include those outside of the sibling dementia caregiving system. Moreover, intergenerational caregiving reciprocity seemed to override troubles brought on by other obligations and burdens of caregiving.

Types of support. Central to caregiving siblings was accessing different kinds of social support, not instrumental support, to help with specific caregiving situations. With these participants, support was made up of various types of comfort and encouragement, and it manifested in three important ways: 1) as emotionally comforting, 2) as mentally validating, and 3) as logistically practical. In regard to emotional comfort, past research on social support found that in challenging situations of crisis and change, emotional support was crucial to deescalating crisis and minimizing negative consequences of the change (Caplan & Killilea, 1976). In addition, Cobb (1976) found that emotional support was particularly important in helping individuals cope with life stress, and could be protective against “extensive life changes” (p. 306). In the current study, for example, participants discussed stressors involved in dealing with the changes their parents were going through. It was communication of emotional support between siblings that seemed to help them believe they were cared for and loved, even with their parents’ progressive cognitive decline. Thus, emotional support from fellow siblings may have served a protective function in the dementia caregiving system.

In addition, participants discussed their experiences of support as mentally validating. This mental validation was an important aspect of social support for

caregivers because it helped to motivate them and maintain high morale in the tough tasks of dementia caregiving. In Cobb's (1976) paradigm of social support, he termed the information that led individuals to feel validated and valued for their contributions *esteem support*. Cobb found that in situations that led to low morale and possible life threats, receiving esteem support seemed to benefit individuals, and in-turn fostered individual motivation and high morale. In this study, participants perceived that siblings provided feedback that substantiated their experiences of the caregiving process, exemplified the trust and belief that they were all in it together, and provided empathy for their siblings' unique situations through the process. The acknowledgement that was given to and received from siblings for their contributions to the caregiving process was validating and supportive. Thus, this mental validation was an important factor in siblings feeling motivated and confident in caregiving due to receiving esteem support from their fellow siblings.

Furthermore, creating an open network of streamlined communication was a logistical practicality. Participants disclosed networks of communication that were important to fostering feelings of being supported by and providing support to their siblings. They talked about the importance of having a common goal, shared information, transparency of responsibilities, and open communication. Having an open network of regular communication between all the siblings was important to participants feeling supported in their roles and linked together with their fellow siblings. Cobb (1976) referred to the information that led individuals to feel they were a part of a network of communication and mutual obligation as *network support*. He found that in situations of

bereavement and loss, as well as those with low morale and threat of death, providing network support was crucial, because like esteem support, it motivated individuals to move forward as a team and increased confidence in their abilities to deal with life changes. Participants in this study revealed that sharing information and having a common ground for making sense of the changes their parents were going through was supportive by helping them to feel more at ease in communicating with their siblings and more confidence in caregiving for their parents with dementia.

Thus, in the current study, another key was accessing different types of social support – separate from instrumental support – because social support helped caregivers cope with specific caregiving situations. In particular Cobb's (1976) three-tiered approach to social support seemed to be most congruent with participants' experiences. Participants in this study had stories that were centered on experiences of emotional care, mental validation, and logistical practicalities of networking – similar to Cobb's three-tiered model of emotional, esteem, and network support – rather than on the provision of services and monetary assistance. Decreased importance of instrumental support for sibling dementia caregivers possibly was because their parents' concerns were being addressed in the residential treatment facilities where parents resided. Therefore, tasks for which caregiving siblings would need more instrumental support (i.e., ADLs) were being taken care of by the treatment facilities. In addition, burdens that weighed on participants and their siblings were related to dealing with the systemic consequences of their parents decline. Accordingly, instrumental support seemed to be less of a central point, while

emotional, esteem, and network support took on the primary focus in helping caregivers cope with the specific tasks of dementia caregiving.

Other sources of social support. Also central to understanding social support was that sibling caregivers had auxiliary informal supports that reinforced the dementia caregiving system. In addition to fellow siblings, caregivers accessed other sources of social support, some of which seemed novel to what has been identified in the literature on caregiver's support sources. Basically, when social support from caregiving siblings was not available, or when supplemental support was needed, caregivers relied on themselves, their children, and their spouses, pets, in-laws, friends and coworkers to hold the space for their emotional, mental, and logistical concerns. Researchers have found that caregivers have relied on a wide reaching network of supporters, including partners or spouses, grandchildren, other relatives, friends or neighbors, supervisors and coworkers, and community supports (House, 1985; Nichols & Zuber, 2011; Raina et al., 2004). Particularly important though was the preference for informal auxiliary support. Siblings in this study sought out informal sources of support over formal support in cases when siblings were either not available, or more support was needed. This is noteworthy because contrary to needing formal instrumental supports in dementia caregiving, they sought out the informal support of those that were close to them. Raina et al. (2004) found that increase in the disabilities of dementia care recipients was associated with decrease in physical and psychological wellbeing of caregivers, and that increased disabilities were associated with greater use of informal support. Further, the more informal support that caregivers received, the better caregivers' psychological wellbeing

was. Moreover, Raina et al. found that the addition of formal care in instances of increased disability in dementia care recipients only marginally influenced the increase in wellbeing for caregiver. So, for dementia caregivers what was crucial to helping them was informal support – whether it was from fellow siblings or auxiliary sources. Informal support reinforced balance and wellbeing in the caregiving system.

Reciprocity of support. Another important facet of social support was caregiving siblings' perceptions of having a doctrine or intergenerational contract that established standards of support in the caregiving system. Although participants communicated stories of burden and competing obligations that hindered their experiences of social support in the dementia caregiving system, they also discussed stories of siblings stepping up to take initiative on responsibilities of dementia caregiving. In either circumstance, what seemed to support them was a broader ideology of reciprocity of support between generations.

Researchers have found that a code or a standard of reciprocity existed in families, which assumed that adult children will provide support to their aging parents in reciprocation for the care that parents have given them through the years (Ikkinck et al., 1999; Tomita et al., 2010). Other researchers have found that between different subsystems in the family there exist different types of reciprocity. Avioli (1989) postulated that balanced reciprocity was a type of reciprocity that was characterized by expectations of the condition of mutual giving and receiving. She believed that sibling relationships represented balanced reciprocity because they were formed based on voluntary attraction and mutual interest, and thus were conditional and dependent on the

quid pro quo nature of the relationship. However, for parents and adult children, she theorized that they experienced generalized reciprocity, or a one-sided unconditional support that was involuntary and given without the condition of receiving.

In this study, shared caregiving between siblings was both part of family expectations and considered a privilege. Participants emphasized the sense of obligation to their parents, modeling an intergenerational duty to care, and desire to honor their parents because of the love and support that they had received as children. These participants saw their parents take care of them through the years, and so they wanted to care for their parents. Additionally, they saw their parents taking time, patience, and care for their grandparents, and they wanted to care for their parents in a similar manner. Rather than generalized reciprocity existing to support their parents, it appeared that a sort of delayed balanced reciprocity was occurring with the participants in this study. Participants wanted to carry on the legacy of care in their families by providing dementia care to their parents as they aged. Thus, the benefits of upholding the expectation of care were maintaining traditions of filial support and familial legacies. The contract between generations helped caregivers bring meaning to their caregiving duties and self-sacrifices. Accordingly, for participants, having a doctrine or intergenerational contract that set standards of support was key to helping them cope with caregiving burdens and competing obligations.

RQ 3: What themes emerge that clarify the dementia caregiving system for adult sibling caregivers? Most essential in clarifying the caregiving system were perceptions held about the nature of parents' cognitive decline and cultural guides for

how caregiving siblings approached the process of dementia care for their parents. These perceptions were important because caregivers were able to receive guidance on how to navigate dementia caregiving through their own observations of their parents' experiences of cognitive decline, rather than relying on formal care macrosystems with no set standards to help caregiving siblings. In addition, caregiving siblings received guidance about dementia caregiving through standards of their ethnic, religious, and generational backgrounds – guidance that has not been addressed in the formal care system.

Making sense of parents' dementia. Caregiving siblings' narratives revealed dimensions of caregiving in the family that related to how they made sense of what their aging parents were going through in the progression of their dementia. Most participants believed that some sort of life event, coupled with their parents' loss of niche or identity in the family system, served as a catalyst to the onset of their parents' dementia.

Although there is a small body of literature that has looked at precipitating life events, literature on the impact of life events is varied. Researchers have found that putting off retirement (a process that to some may be stressful) to older ages (age 65 and older) was associated with decreased risk of developing dementia (Strong, 2013). On the other hand, researchers have found that stressful life events appeared to have had no impact on the onset of dementia (Fountoulakis, Pavlidis, & Tsolaki, 2011; Sundström, Rönnlund, Adolfsson, & Nilsson, 2014). In fact, Fountoulakis et al. (2011) found that some patients who developed dementia experienced low life-events-related stress in the few months before onset (p. 158). Perhaps, the stress of life events had a way of invigorating brains

and enacting protective qualities over transitions that aging adults experienced due to retirement and getting older. In the same vein, it could be that those who elect to live a mentally sedentary lifestyle after retirement (one free of “stress” and minimal changes due to life events) actually set themselves up for cognitive decline that may lead to the development of forms of dementia.

In addition, caregiving siblings discussed how role reversal contributed to their perceptions of the nature of their parents’ dementia. These were situations in which they had to tend to parents’ physical and mental needs as if their parents were children. What is important about this experience of role reversal is that it seemed to alert caregivers to the magnitude of their parents’ cognitive decline. Literature on role reversal in elder care is minimal and mixed, however. Researchers have found that the impact of coming to terms with role reversal and its implications for aging parents’ health can have a deleterious influence on family caregivers assimilation to their caregiving roles in the system of care leading to frustration, fatigue, fear, shame, guilt and anger (Roberts & Straw, 1987). Other researchers have found that perceptions of role reversal existed in situated ideas that undermined the character of elders and disempowered role flexibility and developmental changes that worked to balance family systems as adults moved into old age (Cecchin, 2001). Certainly, the caregivers in the current study expressed their frustration and exhaustion in taking on roles of responsibility for their parents’ daily routines and helping parents emotionally regulate. However, it is possible that the caregivers in this study, impacted by sociocultural standards of a westernized and individualistic U.S. culture, could be viewing their parents’ dementia symptoms from a

lens situated in rigid ideals of parent and child roles. Further, if caregiving siblings' perceptions are situated in infantilizing understandings of parents' aging process, then it is easy to see how the mere concept of role reversal could impact how caregivers make sense of their parents' cognitive decline and make decisions about care.

Also relating to caregivers' perceptions of the nature of parents' cognitive decline was the presence of meaningful interactions with formal care providers. Participants' stories of formal care involvement in dementia caregiving for parents were predominantly negative – they discussed experiences of medication mistakes, difficulties in diagnosis, inconsistencies in care procedures, staff turnover, and struggles to understand the rules and regulations of Medicare/Medicaid. For the most part, interactions with formal care providers were brief and intermittent. Researchers have found that meaningful connections between healthcare providers and family caregivers can promote caregiver wellbeing and positively impact care recipient treatment, especially when interactions include interactive dialogues, collaboration with healthcare providers, and personal quality that help family caregivers and formal care providers feel known and understood for their unique situations (Adkison, 2014). On the other hand, when caregivers did not interact and collaborate in personal ways with healthcare providers, meaningful interactions were missed and the potential positive benefits of connection with formal care providers was reduced. For participants in this study, their negative evaluation of the presence of formal care in the dementia caregiving system may have been due to a lack of meaningful connections with healthcare providers. Participants

in this study relied mostly on informal care, and may have not seen a need for more involvement with formal care services.

Influence of cultural guides. In addition, caregivers relied on broader societal and cultural influences to guide them in the processes of dementia caregiving. Results of this study revealed the importance that religion, ethnicity, and generational differences had on how families perceived the dementia caregiving system. Participants discussed how religion and ethnicity had influenced their connections with their communities, allowed them to uphold family traditions, and provoked conflict in family histories. These associations helped participants establish themselves in greater circles of support and also helped to provide standards of how to address discord in family relationships.

Participants also discussed the intersections between traditional and contemporary modes of connection, idealized childhoods and imperfect adult caregiving situations, and stories of their parents fixed in former ways of being and inability to find new perceptions and ways to experience life. Researchers have found that dementia caregivers may benefit from embracing their religious and ethnic standards, as these principles may provide meaning to caregiving roles and how they make decisions in dementia caregiving system (Henderson & Guitierrez-Mayka, 1992; Weisman de Mamani et al., 2014).

Additionally, in the very limited literature on generational differences, it was found that aging adults who were part of the “silent generation” (those born and raised in the 1925-1945) may experience a process of *migrating in time* – where they must deal with cultural differences in ways that vary significantly from the time they grew up in (Westerhof, 2010). Further, the impact of generational differences may be related to how

individuals self-identified in the process of *migrating in time* and the degree that cultural change was integrated into aging individuals' personal narratives (p. 12). Although some aging adults were open to the new opportunities that *migrating in time* allowed, others identified with the past and felt alienated from post-modern societal changes (Westerhof, 2010). Caregivers in this study emphasized how religion, ethnicity, and generational differences had impacted how they viewed their parents in the dementia caregiving system and the roles they shared with fellow caregiving siblings. Care recipients and their family caregivers could stand to benefit from understanding rigid ideals that foster stagnation in relationships rather than growth and change, as religious, ethnic, and generational principles impact how dementia caregivers perceive their parents' cognitive decline.

Theoretical Explanations

Crucial to linking understanding of caregiving siblings' perceptions and experiences of connection and social support was understanding the dynamics in their family systems. In this study, participants discussed interconnections between themselves and their parents and siblings, as well as auxiliary supports, familial ideologies, and cultural guides that helped them make sense of the dementia caregiving system. All of these interconnections made up the caregiving sibling system. Yet, one of the main concerns of this inquiry is that prior research and models of helping families focused too much on network provisions (social networks that emphasize instrumental connections between dyads in a system) of instrumental support to primary caregivers (Cantor, 1991; Kahn & Antonucci, 1981; Sims-Gould & Martin Matthews, 2007). Researchers have

found that concerns of adult siblings and aging parents have not been adequately addressed because literature has historically focused on commonplace caregiving concerns (such as primary caregiver stress and burden), and there is a lack of original *a priori* ideologies of understanding family caregiving (Mancini & Blieszner, 1989; Whiteman, McHale, and Soli, 2011). Indeed family systems theory has been used to conceptualize presenting concerns of couples and children and parents (Kelly, Maynigo, Wesley, & Durham, 2013; Kovacs, 1988; Roberts et al., 2014; Sturge-Apple, Davies, & Cummings, 2010; Trivette, Dunst, & Hamby, 2010). Yet, there is a gap in the research of family dementia caregiving from a systems theory framework. Researchers have pointed to the need for theory development that applies to family issues in care for aging parents (Mancini & Blieszner, 1989; Whiteman et al., 2011).

Findings in this study accentuate the necessity for a systems framework in understanding the needs of adult siblings caregiving for aging parents with dementia. In family systems theory, individuals' problems exist in interconnections between the family members that are part of the system. In order to more fully understand concerns of individuals, the nature of connections and communications in the family must be deciphered because individuals cannot be fully understood separate from the context of the family system (Cox, 2010; Hecker et al., 2003; Nichols, 2004; Whiteman et al., 2011). Thus, when caregivers to aging parents with dementia feel stress and burden, it can be conceptualized not as only a primary caregiver issue, but rather as a family issue. Connection and support for one caregiver likely influences – and is influenced by – other caregiving siblings in the system. Researchers have demonstrated the need to understand

the problems that sibling caregivers experience in parent-caring systems, rather than from the perspective of a primary caregiver member (Gan & Schuller, 2002). These researchers found that it was through the interactions of all family members (including siblings) that decisions were made about whom, how, and when care would take place. Thus, caregiving responsibilities and stresses must be viewed in the context of the whole family, not understood just as the experience of one caregiver.

Although using a family systems paradigm may be an ideal approach to understanding the dynamics of adult siblings in dementia caregiving systems, researchers have found that it is often underutilized because of the challenges in operationalizing structures of the family (e.g., sibling constellations, hierarchies, boundaries, and coalitions; Whiteman et al., 2011). Nonetheless, researchers have found that of the many different theoretical modalities for understanding relationship dynamics, family systems frameworks seem to be the most relevant to addressing sibling relationship concerns (Mancini & Blieszner, 1989; Whiteman et al., 2011). Family systems paradigms could help in understanding developmental transitions and adaptations to change in the systems of adult siblings taking on the care of their aging parents with dementia. Exploration of the literature has found that this has not been undertaken to date, and framing inquiry from a family systems paradigm could be a starting point for which to understand adult sibling dementia caregiving system.

Additionally, family systems paradigms could be used to understand the broad impact of social and cultural standards on the caregiving process. In family systems theory, larger systems consisting of cultural, political, environmental, and contextual

systems are called suprasystems (Hecker et al., 2003). Family systems paradigms often ignore this larger system. However, Whiteman et al. (2011) found a small body of literature that examined the influence of cultural forces on sibling relationships. He noted in his review of this literature that family obligations were linked to closer connections in sibling relationships in minority families in the U.S. In addition, he observed cultural differences in how siblings responded to caregiving roles based on concepts of rivalry and competition in non-Western sibling groups (Whiteman et al., 2011). Hierarchical forces in the family that influenced how family members would respond in caregiving roles were grounded in rivalry and competition. In the current study, dynamics like the ones above frequently arose in participants' stories. Yet these external influences of social and cultural standards go beyond family systems frameworks, and take on contextual influences of the ecological systems in which families exist.

When looking at how the data emerged in the current study, patterns of interaction and communication began to unfold that were indicative not only of family system elements, but that could also be explained by ecological systems. Adult sibling caregivers' experiences in the dementia caregiving system mirrored the microsystems, mesosystems, exosystems, and macrosystems of Bronfenbrenner's (1979) model. There has been criticism, however, about using his model in that it flattens the dynamic multiple dimensions of the adult sibling relationship, especially as it transitions into a dementia caregiving relationship (Watling Neal & Neal, 2013). The problem here is that understanding interconnections and flow between different systems is based on the different levels of the system being "nested" within each other. Researchers have argued

for a systems model that takes into account family systems, education systems, community systems, and really any system that might apply to a person. They argue that rather than being a series of systems influenced by the next in nested and concentric circles, new systems should be networked in overlapping and non-nested subsystems or mesosystems. Watling Neal and Neal (2013) termed their model the Networked Model of Ecological Systems.

At first glance, the Networked Model of Ecological Systems seems to be a good fit for understanding the dynamics that adult caregiving siblings, like participants in this study, confront in dementia caregiving. After all, the model takes into account the juxtaposition to multiple circles or systems that dementia caregiving could have. Additionally, it accounts for global influences like the natural changes that occur in systems because of the passing of time - Westerhof (2010) described this systemic influence on aging adults as *migrating in time*. Further, Watling Neal and Neal (2013) proposed that contrary to Bronfenbrenner's setting-focused network model, the Networked Model of Ecological Systems is social interaction-focused and aims to identify patterns of communication and connection between individuals within and between subsystems that more closely reflect system members' reality by integrating "precise tools of social network analysis" (p.733). Theoretically, the model could work for adult caregiving siblings because it would provide structure in which to gather caregivers' stories about various systems and systems' members, elucidate connections between systems (that may vary dependent on perspectives of system members), and

ultimately illustrate a human ecological system that mirrors the unique dynamics of dementia caregiving systems.

In Figure 1, a basic example is presented of how the Networked Model of Ecological Systems could be applied to the dementia caregiving system. In this model a focal caregiver is identified, and then asked to talk about the various systems and members who make up those systems.

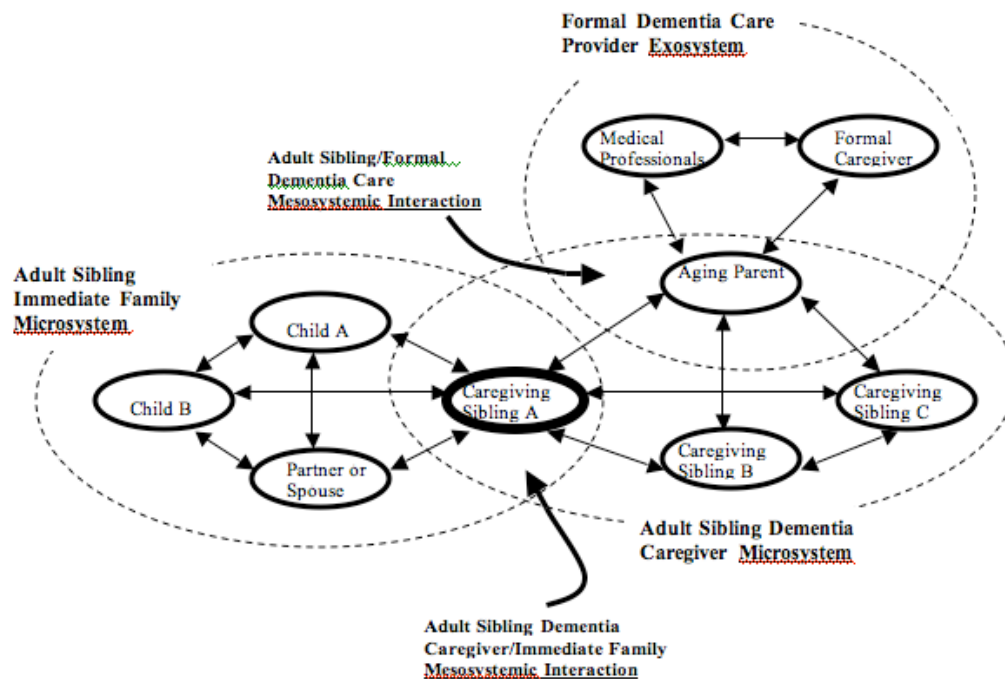


Figure 1. Dementia Caregiving System Model Adapted from Watling Neal and Neal (2013) Networked Model of Ecological Systems.

In Figure 1 the focal caregiver, Caregiving Sibling A, has described two microsystems in which that caregiver is a member. Microsystems are settings in which sets of people are regularly engaged in interaction with the focal caregiver and with each

other (Watling Neal & Neal, 2013). Also identified by Caregiving Sibling A is an exosystem consisting of formal dementia care providers. Exosystems are settings of social interaction that do not include the focal caregiver, but for which there may be direct or indirect interaction. Finally, the mesosystems (the social interactions between individuals of systems) was represented with the overlapping lines of the microsystems and exosystems. The mesosystems represent the fluid interaction between systems – the only part of the model that is not fixed, seemingly.

A complicating factor is that systems of people are not static. Not only do they change overtime, but they also may transition into each other. For example, in Figure 1, Caregiving Sibling A's immediate family microsystem is separate from the formal dementia care provider exosystem. As it is, the communication about formal dementia care is either directly or indirectly through the aging parent to adult caregiving siblings. However, in some microsystems, the partner/spouse of the adult caregiving sibling could become more involved in the process of dementia caregiving, and so the microsystem of adult sibling dementia caregivers would have to widen to include the partner/spouse. However, then that would compromise the meaning of adult sibling dementia caregivers microsystem, which is the family of origin system with its own history of functioning. In the current study, one family experienced this situation when the husband of one of the caregiving sisters stepped up to engage in the routine care of his wife's mother. He had retired and so it made sense for him to take on the weight of responsibility because his wife's mother was living with them and his wife was still employed fulltime. The husband in this example became the liaison between family caregiving and formal care

involvement. Thus, the immediate family microsystem merged with the dementia caregiving siblings' microsystem. Yet, the reality of the situation was that the husband was a part of the dementia caregiving, but not a part of the adult sibling dementia caregivers' microsystem. What is challenging is how to convey this in the Networked Model of Ecological Systems in a way that maintains the meaning of certain microsystems, but also represents the merging of systems for common goals. More importantly, it would be complicated to illustrate in a two-dimensional chart the levels of interaction between sets of people in systems. As evidenced in the narratives of the caregivers in this study, within just their family of origins were different levels of systems with different ways of interacting in mesosystems.

It seems that a three-dimensional kinetic model of the dementia caregiving system dynamics would be a more appropriate way to structure inquiry. Developing that model is beyond the scope of this discussion. However, the Networked Model of Ecological Systems (Watling Neal & Neal, 2013) can provide a visual image of the ecological circles that make up the dementia caregiving system. If the themes that emerged in this study are applied to the networked model, a more specific plan of action emerges for families, counselors, service providers, educators, and researchers to understand what interactions might exist where and how to address them. Figure 2 illustrates a proposed family systems/ecological model of adult sibling dementia caregivers system. In it are three of the predominant microsystems (Individual Caregiver (Internal), Individual Care Recipient (Parent with Dementia – Internal), and Relationships That Carry Individuals

(External)), as well as the formal care exosystem that emerged in the results. It is in the mesosystemic interaction overlap where cross-family themes lie.

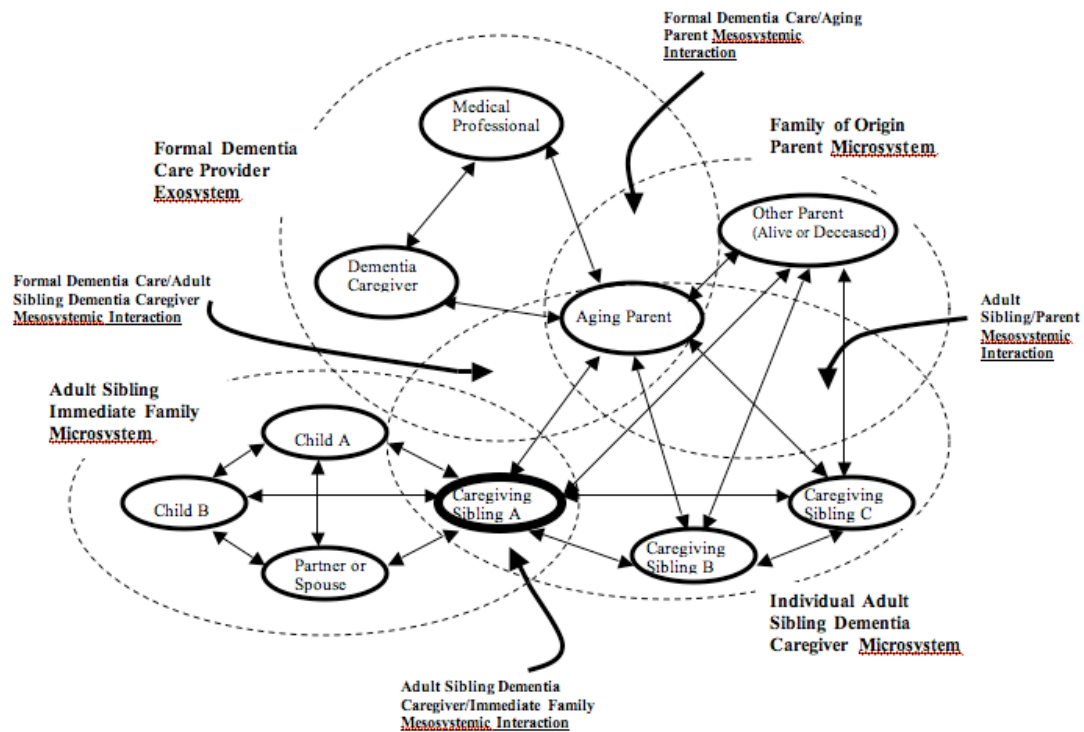


Figure 2. Proposed Family Systems/Ecological Model of Adult Sibling Dementia Caregivers.

For example, in the Adult Sibling Dementia Caregiver/Immediate Family Mesosystem, Individual Caregiver (Internal) cluster themes most readily apply (see Table 3). Thus, individuals working with adult sibling caregivers and their immediate families (partners/spouses and kids), might help caregivers (and other microsystem members) by addressing issues related to caregiving and sibling personality differences, active full lives, and competing obligations, to name a few. Some cluster themes did not fit neatly

into one mesosystem interaction, but rather seemed to influence multiple mesosystem interactions. For example, Relationships that Carry Individuals (External) cluster themes of Third Generation Connection and Wide Reaching Support Network seemed like they would influence interactions in both Mesosystem 1 and Mesosystem 2. Finally, the Cultural Guides cluster that emerged in the data represented overreaching standards and ideals, and were more indicative of the chronosystem, or systems that reflected change or influence across time in all systems (Watling Neal & Neal, 2013).

The proposed family systems/ecological model of adult sibling dementia caregivers fits the findings of this study in that it brings together family system themes into an ecological model that presents a structure through which to understand the complicated interconnections of the adult sibling dementia caregiving system. An advantage of using this proposed combined framework is that it provides a roadmap of not only the settings – or places – that caregivers have been, are now, and will be going in family dementia care, but more importantly it guides individuals to understand what to look for in the interactions once they get to those places. Most important to these systems are the relationships and social interactions that exist within them. Understanding the dynamics of the various existing subsystems or microsystems that exist can help adult siblings, counselors, service providers, educators, and researchers support rethinking and reconnecting about how caregiving siblings' perceive and experience the dementia caregiving system.

Table 3

Thematic Breakdown of Proposed Family Systems/Ecological Model of Adult Sibling
Dementia Caregivers Mesosystem Interactions

Chronosystem	Connections Between Mesosystems	Mesosystems	Clusters and Themes To Explore
Cultural Guides cluster Themes: - Religion and Ethnicity as Guide to Culture - Different Time (Generational) – Relationship with Parents		1) Adult Sibling Dementia Caregivers/Immediate Family	Individual Caregiver (Internal) cluster Themes: <ul style="list-style-type: none"> - Caregiving and Sibling Personality Differences - Active Full Lives - Competing Obligations - Burden versus Fairness - Sibling Closeness/Unique Bond and Alliance - Initiative Taking – Stepping Up - Use of Professional Role/Education
	Relationships that Carry Individuals (External) cluster themes of Third Generation Connection and Wide Reaching Support Network connected Mesosystems #1 & #2		
		2) Adult Siblings/Aging Parents	Relationships That Carry cluster Themes: <ul style="list-style-type: none"> - Roles Through the Years - Contract Between Generations - Support in Sibling System
	Individual Care Recipient (Parent with Dementia) cluster theme of Lack of Niche/Identity in Family System connected Mesosystems #2 and #3		
		3) Formal Dementia Care/Aging Parent	Individual Care Recipient (Parent with Dementia –Internal) cluster Themes: <ul style="list-style-type: none"> - Life Events as Catalyst - Formal Care as a Resource or Another Problem
		4) Formal Dementia Care/Adult Sibling Dementia Caregiver	Individual Care Recipient (Parent with Dementia – Internal) cluster Themes: <ul style="list-style-type: none"> - Role Reversal - Formal Care as a Resource or Another Problem

Implications

Conclusions that can be drawn from this research impact how the tasks of dementia care are handled, but more importantly how caregiving systems can integrate and support the adult children who are often expected to take on responsibilities of dementia caregiving to aging parents. The significance of this research can be applied to counselors, healthcare providers, researchers, and counselor educators. Below, implications for each of the aforementioned groups will be discussed.

Counseling Implications

In counseling caregiving siblings through the dementia care process, counselors should expand their view from a primary caregiver paradigm to a systems model of helping. Specifically, counselors must assess family members in the system, their roles in the family of origin and their levels of involvement in dementia caregiving, and understand the connections, types of support, and ecological influences on the interconnections of system members. By doing so, counselors can gain a context for which to understand the presenting concerns of families, and develop a comprehensive treatment plan that involves all system members at each of the levels of involvement in dementia caregiving. Thus, working with sibling dementia caregivers will honor the roles that all siblings play in the system and provide context for which to understand the etiology of presenting concerns and ultimate directions of treatment planning for dementia caregivers.

In addition, counselors should be aware that family solidarity is not a given, and attend to understanding the influence of family of origin roles, communication styles,

and possible distorted images of earlier relationships. Only by understanding these dynamics can counselors help caregiving siblings get to the root of conflicts that threaten the caregiving system, begin to diffuse misunderstandings, and rebuild new connections that support collaboration and balance in dementia caregiving.

Moreover, results of this study revealed the importance that religion, ethnicity, and generational differences had on how families cope with eldercare. Care recipients and their family caregivers could benefit from understanding rigid ideals that foster stagnation in relationships rather than growth and change. Counselors could help caregiving siblings and their aging parents acknowledge and understand these cultural dynamics within the context of the family system.

Health Care Service Implications

In providing medical care and ADL assistance to aging adults with dementia, health care providers must broaden their treatment in two ways: 1) consider the history of familial relationships and connections that have manifested dis-ease (Hay, 2004), and 2) begin to look at dementia care preventatively. Indeed, one neurologist, Dr. Peter Whitehouse, found in physiological studies of dementia that the roots of dementia are not necessarily in neurons, but in the bio-psychosocial processes and human-environment relationships that support or sabotage the integration and interdependence of people in their life systems (2008). By looking into the systems that contain the mysteries of dementia and attending to the patterns of connection and communication, health care providers can help foster improved harmony and balance in lives of adult siblings caregiving for parents with dementia.

Research Implications

Researchers must adopt a theoretical paradigm that is sound and appropriately addresses the complexity of the dementia caregiving system. Results from this study show the importance of working from a multidimensional systems paradigm, rather than a primary caregiver network model. Moreover, it appears that beyond the family of origin system, there are broader societal and cultural elements are at work that influence dementia caregiving systems. Using a model such as the proposed family systems/ecological model of adult sibling dementia caregivers could help to map the intersecting subsystems that make the dementia caregiving system. Additionally, such a model could provide a guide for exploring themes within and between system interactions. Further, this more comprehensive system model could help researchers in developing a priori ideas about how family caregivers will respond based on the interconnections and multiple dimensions of the system. Researchers could clarify quantitative findings of caregiving not only to understand family-specific dynamics, but also to examine the multicultural aspects of caregiving.

Counselor Education Implications

Future counselor educators must include issues related to gerontological counseling and family eldercare issues in courses and trainings. Topics to be covered could include problems faced by family caregivers, specifically adult siblings, such as stresses stemming from presence or lack of social support and/or instrumental support, filial expectations of care, family of origin roles, ideals of family structure, caregiving sibling characteristics, and specific challenges related to caring for aging parents with

forms of dementia. In addition, counselors-in-training would benefit from learning the best practices for addressing caregiving issues with aging adult, as well as the most relevant means to access and help sibling caregivers to aging parents. Counselor educators must mentor counseling students to understand the important issues to consider when teaching and supervising those who will work with clients and their families on gerontological caregiving issues.

Future Recommendations

Future practice and research must approach dementia caregiving research from a family network systems model of sorts. In particular focus should be placed on understanding and working with the dimensions of the sibling subsystem because it is the adult children of aging parents who often take on caregiving. It is recommended that counselors, service providers, and researchers could benefit from using a theoretical framework that combines understanding of networked ecological systems with familial dynamics in dementia caregiving systems, as well as broader system influences. This combined family systems/ecological model of adult sibling dementia caregivers could provide a relevant, contextual, and solid theoretical foundation for understanding clients' presenting concerns and to make clinical decisions, as well as bring meaning to quantitative findings of dementia caregiving. Using an integrated family network systems model may help adult sibling dementia caregivers heal past misunderstandings and promote connections that foster harmony and social support in caregiving systems.

Additionally, attention must be turned to dementia caregivers' experiences of social support in their families – specifically in their sibling groups. Dementia care

providers in this study repeatedly emphasized the importance of emotional, esteem, and network support – a three-tiered model of social support – that they counted on from their fellow caregiving siblings. Rather than asking “the primary caregiver” about their experiences in dementia care, counselors and service providers must assess what the familial system of care is, who makes up the system, what their roles are at any level of involvement, and understand pathways of communication. By doing so, they may foster positive change in the family system that supports caregiving for their aging parents.

Researchers must examine the protective qualities of social support from the context of the sibling subsystem. The literature on the importance of specific types of social support in certain life changing situations is small and there is virtually no information on social support between adult sibling caregivers for parents with dementia. Conducting research on social support needed to weather life changes such as aging, physical and cognitive decline, and death, could inform systems theories and family practice on familial dementia caregiving.

Moreover, assessing and understanding the individual, wide-reaching, and broader ethnic, religious, and generational influences on dementia caregiving is essential. There is a deficit of information on personal qualities that caregivers bring to dementia care with their professional and educational resources and their contributions to dementia caregiving. In addition, it is not entirely understood the strength of wide-reaching support networks in dementia caregiving systems. Further, there is a dearth of literature on the impact of ethnic, religious, and generational influences on how aging parents and adult children communicate, and how these elements influence shared caregiving between

siblings. In order to understand these broader forces, practitioners and researchers must create inquiries that examine the many levels of the system of care and place high priority on implementing practices that validate idiographic manifestations of individual strengths, supportive resources, and cultural guides in the process of familial dementia care.

Limitations

The qualitative approach to the current study lends itself to certain limitations. One limitation was that findings were not generalizable. Information that was collected consisted of descriptive narratives of individuals' subjective experiences. The purpose was to gather in-depth understanding of the phenomena that emerged related to adult siblings' individual experiences of sibling connection and social support in the caregiving process. Thus, data were illustrative of the participants' experiences, and not representative of all caregiving siblings.

Additionally, the data were not generalizable because convenience sampling was used. In the current study, participants were recruited through word-of-mouth among the researchers family members, friends, colleagues, and acquaintances. Although, convenience sampling was appropriate to the design and purposes of this study, it was not possible to generalize findings to the larger population of sibling caregivers. However, the researcher made efforts to establish transferability, which is the establishment of qualitative data as representative of smaller and particular environments and people. Shenton (2004) recommends that "sufficient contextual information about the fieldwork" be provided to promote transferability of qualitative results (p. 69). Thus, the researcher

provided detailed descriptions of sibling dyads so that future readers of this research (i.e., dementia caregivers, practitioners, and researchers) will understand the contextual factors in which to understand the results of this study, and thus make transfers to their own fields of work, where applicable.

A second limitation in this study was that participants were selected from a specific region and from the pool of the researcher's close connections. Therefore, it was possible that the participants responded in situated ways based on environmental influences (including, but not limited to economic, political, societal, cultural, racial, and gender influences) of where they were located, as well as the connections with the researcher's family members, friends, colleagues, and acquaintances. It is possible that responses could be biased because of the social norms that existed in certain families, communities, and geographic locations. Also, responses could be biased because of the relationship connections between participants and the researcher's close connections.

A third limitation relates to response bias due to the method in which data were collected. Face-to-face interviews were conducted, which might have led participants to respond in more desirable ways than they would if they were answering questions in a phone interview, email correspondence, or questionnaire. As indicated above, researchers doing phenomenological inquiry recommended face-to-face interviews that were in a safe, secure, and private location (Smith & Osborn, 2007). Having incorporated face-to-face interviews in the data collection allowed participants to feel that the information they shared would be protected, and it provided personal and comfortable approaches to build rapport, so that honest disclosures could be obtained. Still, even with the measures put in

place to provide secure, private, confidential environments for the interviews, some participants may have felt the need to respond more desirably. To help limit the bias of social desirability, the researcher ensured that interview data were kept confidential, were not shared with their other caregiving siblings, and that data were coded and all identifiers were removed.

Conclusion

Findings of this study support an expanded way of helping and understanding adult sibling dementia caregivers' experiences and perceptions of sibling connection and social support from a family systems/ecological model. It was found that adult sibling dementia caregivers, counselors and healthcare providers, counselor educators, and researchers studying dementia and caregiving may benefit from using a family systems/ecological model of adult sibling dementia caregivers to understand and address presenting concerns of clients, as well as pressing questions of dementia and dementia care. On a basic level, participants expressed experiences of sibling closeness and connection, as well as multiple types of social support from fellow sibling caregivers. On a broader level, their stories shed light on the multi-dimensional influence of personal resources and cultural guides that help sibling caregivers care for their aging parents, and care for each other.

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APPENDIX A
RECRUITMENT LETTER

The University of North Carolina Greensboro

Exploration of Experiences of Caregiving for Parents with Dementia

Recruitment Letter

Hello, my name is Megan Seaman and I am a doctoral student at The University of North Carolina at Greensboro. I am writing to request your participation in my dissertation research project.

The purpose of this exploratory qualitative study is to explore the perceptions and experiences of sibling connection and social support between caregiving siblings to aging parents with dementia. The researcher will seek information from each sibling in families who are currently caring for aging parents with dementia – specifically, those who are participating in the care of one parent with dementia. Additionally, the researcher seeks family caregivers in which a sister and brother are willing to participate in interviews that will be compared. The location of the interview will be your residence, or other private, secure, confidential, and distraction-free location of your choosing.

As a participant, you and your sibling will engage in separate 90-minute semi-structured interviews. Interviews will be documented through audio recording, demographic questionnaire, and note-taking by the interviewer. Both you and your sibling will be asked a structured set of questions, but some questions may vary depending on the unique responses to each of your questions. Although, each of your interviews will be compared, they will be confidential between you and the interviewer. This means that the interviewer will not share what you say in your interview with your sibling(s). The total estimated time of the entire investigation is about 2.5 hours. For your benefit, you will receive a packet of information detailing resources available to help you and your family address the concerns you have in caring for your aging parents with dementia. The packet will include helpful articles and checklists, as well as contact information of local and national organizations for caregivers to aging adults with dementia. There will be no financial compensation for your participation.

Please note that your participation in this research project is voluntary. The University of North Carolina at Greensboro's Institutional Review Board makes sure that studies with people follow federal rules. Should you have any concerns about your rights and how you are being treated, please contact Christy McGoff in the Office of Research Integrity at UNCG at (336) 256-4231. Questions, concerns or complaints about this project or

benefits or risks associated with being in this study can be answered by my mentor, Dr. James Benshoff, who may be contacted at (336) 334-3424.

If you have questions, want more information, or would like to be a part of this investigation, please contact me, Megan Seaman, at meganseaman@hotmail.com and/or by phone at (216) 402-7372. I thank you for your time and I hope to have your every consideration.

With gratitude,

Megan Seaman, MS, NCC, RYT

APPENDIX B

DEMOGRAPHIC QUESTIONNAIRE

Caregiving Siblings Demographic Questionnaire

Directions: Please complete the following questions accurately and honestly. Your responses will help the interviewer direct the interview discussion. Note that your responses are confidential between you and the interviewer and **WILL NOT** be shared with your sibling who has also agreed to participate in the study.

1. What is your gender? ☐ Female ☐ Male ☐ Transgender

2. What is your race/ethnicity?

☐ Hispanic/Latino(a) ☐ Non-Hispanic/Latino(a)

☐ American Indian or Alaska Native

☐ Asian

☐ Black or African American

☐ Native Hawaiian or Other Pacific Islander

☐ White

3. Age (years)? _____

4. Education Level:

☐ Grade school ☐ HS Diploma ☐ GED ☐ Some College ☐ Associate

☐ Bachelor ☐ Master ☐ Ph.D. ☐ Technical School/Training

5. Employment status? ☐ Full-time ☐ Part-time ☐ Unemployed

If employed, how many hours/week do you work? _____

6. Relationship status?

☐ Single ☐ Married ☐ Divorced ☐ Widowed ☐ Significant Other

7. Who makes up your **immediate family** (list first names, ages, and relations to you)?

8. Who makes up your **family of origin** (list first names, ages, and relations to you)?

9. What is the gender of your parent who you are caring for?

☐ Female ☐ Male ☐ Transgender

10. What is the age of your parent who you are caring for (years)? _____

11. Proximity to parents?

☐ Within 5 miles ☐ Within 6 - 20 miles ☐ Within 21 – 100 miles ☐ More than 100 miles

12. Estimate the numbers of hours/week that you spend on caregiving tasks (hours)? _____

13. Frequency of contact with parents (number of contacts/week)?

_____ Phone calls _____ Face-to-face visits _____ Text/email correspondence
_____ Other

14. How long has your parent had symptoms of dementia? (Please list the number years and/or months)

15. How long have you been caregiving for your parent? (Please list the number of years and/or months)

16. Describe the types of caregiving responsibilities that you have each week or month in caregiving:

17. Describe the type of caregiving involvement or role you have in the care of your parent with cognitive decline or dementia:

18. In the process of caring for your parent with dementia, who do you receive support from and what kind of support do they give? (Support may be emotional, informational, and appraisal supports, and/or may also include instrumental tasks):

19. On a scale of 1 to 10 ("1" = no support at all, to "10" = over and beyond support), how much support do you feel from the supporters described in question 18? (Please list individual's name and their score next to their name):

20. On a scale of 1 to 10 ("1" = distant and dissociated, to "10" = very close and connected), how close are you with your siblings? (Please list the name of each of your siblings and their score next to their name):

21. On a scale of 1 to 10 ("1" = not involved at all, to "10" = routinely and consistently involved), how do you perceive your siblings' caregiving involvement? (Please list the name of each of your siblings and their score next to their name):

22. How much time do your siblings spend on caregiving? (Please list the average number of hours per week each sibling spends caregiving next to his or her name):

23. What contributions to the caregiving do your siblings make – what kinds of things do they do? (Please list each sibling name and the types of contributions to caregiving):

24. How close in proximity do your siblings live to your aging parent with dementia? (Please list the approximate number of miles each sibling lives next to his or her name):

25. How do you perceive your siblings' connections with you and with each other?

26. How do you perceive your siblings' social support to you and to each other?

27. What other family members or other caregivers are involved with the care of your parent with dementia?

Thank You For Your Response!

APPENDIX C

INFORMED CONSENT FORM

UNIVERSITY OF NORTH CAROLINA AT GREENSBORO

CONSENT TO ACT AS A HUMAN PARTICIPANT

Project Title: Caring for the Caregiver: Exploration of Social Support and Sibling Connection in Relationships of Adult Siblings Caring for Aging Parents with Dementia

Project Director: Megan Seaman, MS (Principal Investigator and Student Researcher), James Benshoff, Ph.D. (Faculty Advisor)

Participant's Name:

What is the study about?

This is a research project. The purpose of this exploratory qualitative research project is to explore the perceptions and experiences of sibling connection and social support between caregiving siblings to aging parents with dementia. There are three primary objectives of the proposed study. The first objective is to explore the perceptions and experiences of sibling connections in the caregiving sibling system in order to understand the differential circumstances that siblings have, while caring for parents with dementia. The second objective is to investigate the social support (or lack thereof) that is perceived and experienced among siblings in the caregiving sibling system, as it may relate to the dementia caregiving process. The third objective is to understand the emergent themes that clarify caregiving siblings' perceptions and experiences of sibling connection and social support between siblings.

Why are you asking me?

In order to understand the caregiving sibling system, the researcher will seek information on the experiences of caregiving from each sibling in families who are currently caring for aging parents with dementia – specifically, those who are participating in the care of one parent who has dementia, and whose spouse is no longer living or part of the provision of care. Additionally, the researcher seeks family caregivers in which, at the very least, a sister and brother are willing to participate in interviews that will be compared, because past research has found gender differences in experiences of caregiving. Moreover, examining the perceptions and experiences of each of the siblings

in the family from a family systems framework represents a divergence from typical models that look at primary caregivers. Because of the newness of this approach in looking at caregiving sibling systems for aging parents with dementia, the researcher will use a qualitative model in order to discover how sibling connection and social support is perceived and experienced by caregiving siblings and the emergent themes that clarify it.

What will you ask me to do if I agree to be in the study?

As a participant in this investigation, you and your sibling will engage in separate 90-minute semi-structured interviews of your experiences caregiving for your parent with dementia. The interviews will occur in your home, or other private and secure location of your choosing. The semi-structured interviews will be documented through audio recording, demographic questionnaire, and note-taking by the interviewer. Both you and your sibling will be asked a structured set of questions, but some questions may vary depending on the unique responses to each of your questions. Although, each of your interviews will be compared, they will be confidential between you and the interviewer. This means that the interviewer will not share what you say in your interview with your sibling(s). Additionally, you will receive a follow-up message inviting you to review your transcribed interviews for accuracy, and then will be sent the final results of the study at its completion. The total time (including referral, recruitment, semi-structured interviews, follow up transcription review, and receiving results) will take approximately 2.5 hours.

Is there any audio/video recording?

The semi-structured interviews will be audio recorded using a digital audio recording device. Because the interviews will be audio recorded, the researcher will maintain confidentiality of the recordings by keeping them stored on the researcher's computer, which will be password protected, and for which only the researcher will have access. In addition, the researcher will destroy the digital audio files of interviews after they have been transcribed, coded, checked for quality assurance, and data analysis has been completed. Because your voice will be potentially identifiable by anyone who hears the tape, your confidentiality for things you say on the tape cannot be guaranteed although the researcher will try to limit access to the tape as described above.

What are the risks to me?

The Institutional Review Board at the University of North Carolina at Greensboro has determined that participation in this study poses minimal risks to participants. In particular, a minimal risk may be that participants will have to talk about the negative aspects of caregiving, including the experience of lack of connection and social support in the caregiving process and other issues going on in the system of care for their parents with dementia. This could have the impact of bringing up hard feelings, anger, resentment, sadness, sibling rivalry, parent favoritism, etc. (Kahn & Bank, 1981; Matthews & Rosner, 1988; Russo, 2010; Schulman, 1999). If you have questions or

concerns about risks, you may contact James Benshoff, Ph.D. (Faculty Advisor), who may be reached at (336) 334-3423 and benshoff@uncg.edu.

If you have any concerns about your rights, how you are being treated, concerns or complaints about this project or benefits or risks associated with being in this study, you may contact the Office of Research Integrity at UNCG at (336)-256-1482.

Are there any benefits to society as a result of me taking part in this research?

A societal benefit of doing this study might be to inform mental health practitioners of the important issues that families face when collaborating in dementia care. Additionally, practitioners might learn important patterns of connection between caregiving siblings that may inform best practices and therapeutic interventions with families. Moreover, patterns and themes may be revealed that help to uncover the differences between positively- and negatively-adjusted caregiving systems, and thus inform the development of adaptive family functioning in caregiving systems.

Are there any benefits to *me* for taking part in this research study?

There are no direct benefits to participants in this study.

Will I get paid for being in the study? Will it cost me anything?

There are no costs to you or payments made for participating in this study.

How will you keep my information confidential?

Additionally, because the interviews will be audio recorded, the researcher will maintain confidentiality of the recordings by keeping them stored on the researcher's computer, which will be password protected, and for which only the researcher will have access. In addition, the researcher will destroy the digital audio files of interviews after they have been transcribed, coded, checked for quality assurance, and data analysis has been completed. Informed consent documentation, demographic forms, transcriptions, and notes will be kept in a folder and stored in a locked file cabinet at the researcher's home office. All information obtained in this study is strictly confidential unless disclosure is required by law.

What if I want to leave the study?

You have the right to refuse to participate or to withdraw at any time, without penalty. If you do withdraw, it will not affect you in any way. If you choose to withdraw, you may request that any of your data which has been collected be destroyed unless it is in a de-identifiable state.

What about new information/changes in the study?

If significant new information relating to the study becomes available which may relate to your willingness to continue to participate, this information will be provided to you.

Voluntary Consent by Participant:

By signing this consent form you are agreeing that you read, or it has been read to you, and you fully understand the contents of this document and are openly willing consent to take part in this study. All of your questions concerning this study have been answered. By signing this form, you are agreeing that you are 18 years of age or older and are agreeing to participate, or have the individual specified above as a participant participate, in this study described to you by Megan Seaman (Principal Investigator and Student Researcher).

Signature: _____ Date: _____

APPENDIX D

RESOURCE PACKET

**Caregiving Siblings
Resource Packet**



Compiled by
Megan M. Seaman, MS, NCC, RYT

University of North Carolina at Greensboro

Fall 2013 – Spring 2014

MCI and Forms of Dementia Defined

Cognitive Health: Cognitive health is a term used to define the state of optimal and independent brain functioning. The CDC and the Merck Company Foundation (2007) defines cognitive health as the “combination of mental processes we commonly think of as ‘knowing’ and includes the ability to learn new things, intuition, judgment, language, and remembering” (p. 5). Therefore, maintaining cognitive health is important for individuals to be able to think coherently and make decisions independently.

Mild Cognitive Impairment (MCI): Mild cognitive impairment is when individuals have difficulties with thinking and memory that do not interfere with daily living (U.S. National Library of Medicine, 2012).

Signs & Symptoms of MCI

- Difficulties in multitasking
- Challenges in problem solving and decision-making
- Troubles remembering recent events
- Taking more time than usual to perform tasks

Dementia: Dementia can be defined as loss of brain functioning that affects memory, thinking, communication, judgment, and behavior (U.S. National Library of Medicine, 2012). Psychologically speaking, the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision* (American Psychiatric Association, 2000) defines specific criteria that must be met in order to differentiate dementia symptoms from delirium (an acute confusion state). These include that individuals must experience memory loss and decline in at least one area of functioning, including speech and understanding language, recognition and identification of objects, motor activity, thinking abstractly and making decisions. In addition, symptoms must interfere with multiple areas of daily life.

From a medical point of view, the Alzheimer’s Association (2011a) broadly describes dementia as a condition in which brain cell connections become damaged so that they can no longer provide and receive feedback between cells and can no longer take in and use nutrients for energy production within the brain cells. Furthermore, it underscores that the occurrence of forms of dementia, including AD, is not a normal symptom of aging. Rather, it is a symptom of abnormal physiological changes in the brain (Alzheimer’s Association, 2011a). Consequently, aging adults who are developing forms of dementia, as well as their adult children who care for them, will have to deal with self-care and caregiving duties that are not typical of normal aging.

Signs and Symptoms of Dementia

- **Mild** (i.e., interfere with daily living, but that still allow aging adults to function independently)
 - Decreased memory, first appearing as forgetfulness
 - Difficulty with language and communication
 - Challenges with perception and understanding
 - Changes in emotional expression and behavior or personality
 - Decline in cognitive skills of abstract thinking, judgment, and activities that take more thought, like calculating and planning
 - Difficulty in performing tasks that used to be easy or learning new things
 - Getting lost in familiar places, misplacing things, or losing interest in things that used to be enjoyable
- **Moderate** (i.e., interfere with independent living)
 - Experience of sleeplessness and restlessness
 - Difficulty performing Instrumental Activities of Daily Living
 - Forgetting details of current events and life history;
 - Exhibiting behavior changes including arguments, striking out, and violent behavior
 - Experiencing mental health concerns including hallucinations, delusions, depression, and agitation
 - Confusion with time or place
 - Difficulty in reading and writing and communicating with words
 - Poor judgment and inability to differentiate safely
 - Social withdrawal
- **Severe** (i.e., symptoms are those where aging adults with dementia can no longer independently care for themselves)
 - Difficulty performing Activities of Daily Living
 - Problems remembering and recognizing family members
 - Decreased understanding
 - Trouble with comprehending visual images and spatial relationships
 - Incontinence and swallowing problems
 - Persistent restlessness and talkativeness
 - Hallucinations and experiencing paranoia
 - Presenting unreasonable anger and combativeness
 - Wandering
 - Waking the caregiver
 - Dementia-related pneumonia being the primary cause of death



Risk Factors for Dementia

- Age (65 or older)
- Family History (first degree relative)
- Genetic Heritability (Cholesterol gene, APOE)
- Preexisting Conditions (MCI and Cardiovascular disease)
- Head Traumas and Brain Injuries

Treatments and Care for Dementia = End of Life Care

1. Medical Management: Involves assessing what their needs are, making decisions about potential plans of action, and active engagement in appropriate treatment options. It may include:

- Integrating co-existing conditions in treatment planning
- Coordinating care among formal and informal caregivers
- Using supportive services, activity groups, adult day care, and counseling
- Medication maintenance

2. Modification of Lifestyle Preferences: Involves instituting lifestyle changes of individuals with dementia. It may include:

- Changing to a vegetarian and low-fat diet to mitigate some of the problems or even prevent the occurrence of symptoms
- Regular physical exercise
- Participation in mental activity to slow cognitive decline

3. Fostering Quality of Life: Involves supporting the best circumstances for a safe and happy life for dementia patients' physical experiences, as well as their cognitive functioning. It may include:

- Ensuring safe and comfortable surroundings in which aging adults' IADLs and ADLs are met
- Make available some form of social connection, both in-home and in residential services
- Provide meaning-making experiences
- Fostering meaningful family connections



Organizations and Agencies Specializing in Dementia Care

Local

Ohio

Stone Gardens – An Assisted Living Residence
27090 Cedar Road
Beachwood, OH 44122-1156
Phone: (216) 292-0070
Website: <http://www.stonegardens.org/>

Montefiore – A Non-Profit Healthcare and Senior Living Community
(Rehabilitation Services, Long-term/Short-term Care, Memory Care, Assisted Living)
1 David N. Myers Pkwy.
Beachwood, OH 44122
Phone: (216) 360-9080
Website: <http://www.montefiorecare.org/>

Menorah Park – Center for Senior Living (Rehabilitation Services, Home Health Care, Adult Day Care, etc.)
27100 Cedar Road
Cleveland, OH 44122
Phone: (216) 831-6500
Website: <http://www.menorahpark.org/>

Elmcroft of Sagamore Hills (Assisted Living and Memory Care)
997 West Aurora Road
Sagamore Hills, Ohio 44067
Phone: 330-908-1166
Website: <http://www.elmcroft.com/community/elmcroft-of-sagamore-hills/>

Elmcroft of Medina (Assisted Living and Memory Care)
1046 North Jefferson Street
Medina, Ohio 44256
Phone: 330-721-2000
Website: <http://www.elmcroft.com/community/elmcroft-of-medina/>

Elmcroft of Lorain (Assisted Living and Memory Care)
3290 Cooper Foster Park Road
Lorain, Ohio 44053
Phone: 440-960-2813
Website: <http://www.elmcroft.com/community/elmcroft-of-lorain/>

Gardens at Westlake Senior Living (a Spectrum Retirement Community – Independent Living Community)
27569 Detroit Rd.
Westlake, OH 44145
Phone: (440) 249-4607
Website: <http://www.gardensatwestlake.com/>

Homewood Residence at Rockefeller Gardens (Assisted Living Source community – Memory Care)
3151 Mayfield Road
Cleveland Heights, OH 44118
Phone: (216) 321-6331
Website: <http://www.brookdaleliving.com/homewood-residence-rockefeller-gardens.aspx>

Emeritus at Brookside Estates (Assisted Living Source community – Memory Care)
15435 Bagley Road
Middleburg Heights, OH 44130
Phone: (440) 887-1125
Website: <http://www.emeritus.com/ohio/middleburg-heights-retirement-community/emmeritus-brookside-estates>

Senior Helpers of Cleveland - Independence (Memory Care and Home Care)
4807 Rockside Rd. Suite. 230
Independence, OH 44131
Phone: (216) 453-1040
Website: <http://www.seniorhelpers.com/cleveland-south/>

Connecticut

Emeritus at Litchfield Hills (Assisted Living Source community - Independent Living Community and Memory Care)
376 Goshen Road
Torrington, CT 06790
Phone: (860) 489-8022
Website: <http://www.emeritus.com/connecticut/torrington-senior-living/emmeritus-litchfield-hills>

The Village at Brookfield Common (Assisted Living Source community – Memory Care)
246A Federal Road
Brookfield, CT 06804
Phone: (203) 885-7460
Website: <http://www.villageatbrookfieldcommon.com/>

Fairfield County Home Care (Home Care)
12 Concord Way
New Milford, CT 06776
Phone: (877) 885-9526
Website: <http://www.agingcare.com/local/Fairfield-County-Home-Care-New-Milford-Home-Care-CT>

Rhode Island

West Bay Retirement Living (Assisted Living Source– Independent Living and Memory Care)
2783 West Shore Road
Warwick, RI 02889
Phone: (401) 739-7300
Website: <http://www.brookdaleliving.com/west-bay-retirement-living.aspx>

Sakonnet Bay Retirement Living (Assisted Living Source– Independent Living and Memory Care)
1215 Main Road
Tiverton, RI 02878
Phone: (401) 624-1880
Website: <http://www.brookdaleliving.com/sakonnet-bay-retirement-living.aspx>

Autumn Glen at Dartmouth (Assisted Living Source community – Memory Care and Assisted Living)
239 Cross Road
North Dartmouth, MA 02747 (33 minutes from Warren, RI)
Phone: (502) 992-8880

National

Alzheimers.gov (2013, January 7). How to pay and plan ahead. Retrieved from <http://www.alzheimers.gov/paying.html>

Alzheimer's Association National Office (Resources for patients and caregivers)
225 N. Michigan Ave., Fl. 17
Chicago, IL 60601
24/7 Helpline: (800) 272-3900
Email: info@alz.org
Website: www.alz.org
CT Chapter site: http://www.alz.org/ct/in_my_community_about.asp
OH Chapter site: http://www.alz.org/cleveland/in_my_community_about.asp

Assisted Living Source (Assisted Living, Independent Living, Nursing Homes, Memory Care, and Home Care – Can search by state)
Phone: (888) 213-2731
Email: information@elderlivingsource.com
Website: <http://www.assistedlivingsource.com/>

CaregiverMN.org (a service of DARTS – Caregiver Resources)
1645 Marthaler Lane
West St. Paul, MN 55118
Phone: (651) 455-1560
Fax: (651) 234-2280
Email: info@caregiverMN.org
Website: <http://www.caregivermn.org/links.htm#2>

National Alliance for Caregiving (Resource clearinghouse for Caregivers to Aging Adults)
4720 Montgomery Lane, 2nd Floor
Bethesda, MD 20814
Email: info@caregiving.org
Website: <http://www.caregiving.org/>

Spectrum Retirement Communities, LLC (Can search by state)
200 Spruce Street, Suite 200
Denver, CO 80230
Phone: (303) 360-8812
Toll Free: 800-686-8465
Fax: (303) 360-8814
Email: info@SpectrumRetirement.com
Website: <http://www.spectrumretirement.com/?page=>

Years Ahead - Home Care (Assisted Living Source affiliate – Home Care Service – Can search by state)

Phone: (877) 719-3056

Website: <http://www.yearsahead.com/content/contact-us/>



New Approaches to Caregiving

Family Systems Approach

When sibling caregivers experience depression or caregiving strain, it is not merely intrapsychic breakdowns of those caregivers that lead to mental health concerns, but rather a failure of the family system unit to function appropriately and prevent those caregivers from mental and physical deterioration. Family systems theorists see problems in families as indications that “something is not working effectively within the family structure or process” (Hecker et al., 2003, p. 51). Problems may arise from structural symptoms such as hierarchy, boundaries, subsystems, and rules. Also, problems may arise from process symptoms like how family members interact and communicate (Hecker et al., 2003).

Strategies:

- Maintain Balance in Family Communication
 - Equal acceptance of change (Positive Feedback)
 - Example: Siblings might begin to change their perceptions of what the family is through positive feedback loops that support a change from a nuclear family to one that includes extended family members.
 - Equal acceptance of maintaining family norms (Negative Feedback)
 - Example: In maintaining important family values, using a negative feedback loop to help implement suggestions and wishes from the aging parents themselves may work to preserve the respect and autonomy of the elders in the family.

Collaborative Caregiving

In effort to examine sibling caregiving that focused on harmony in the relationship, as opposed to conflict, Ingersoll-Dayton et al. (2003) investigated the patterns of collaborative sibling caregiving relationships. They found that equitable sharing of caregiving consisted two main pieces of feedback: 1) collaboration, and 2) shared process functions.

Strategies

- Collaboration
 - Making decisions as sibling caregiving partners, TOGETHER
 - Taking turns in caregiving tasks
 - Creating equitable division of labor
 - Reconfiguring and planning care for their parents
- Shared Process Functions

- Redefining caregiving system (from primary caregiver focus to system of care focus)
- Setting aside time to enjoy the sibling relationship (separate from caregiving tasks for parents)
- Balancing setting boundaries for self-identity and accepting change through letting go of old roles played, and accepting new roles
- Integrating parents' suggestions in the decision-making process

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Relevant Articles and Reports for Caregivers

- 2011 Alzheimer's Disease Facts and Figures, report
- Care for the Family Caregiver: A Place to Start, report
- Collaboration Among Siblings Providing Care for Older Parents, article
- Shared Filial Responsibility: The Family as the Primary Caregiver, article
- Who Takes Care of Mom? Siblings Clash as They Respond to Parents' Aging, article



APPENDIX E

RESEARCH CONFIDENTIALITY AGREEMENT

University of North Carolina at Greensboro

RESEARCH CONFIDENTIALITY AGREEMENT
FOR RESEARCH INVOLVING HUMAN PARTICIPANTS

I _____ have agreed to assist with Megan Seaman for the research project entitled Caring for the Caregiver: Exploration of Sibling Connection and Social Support in Relationships of Adult Siblings Caring For Aging Parent with Dementia **IRB # 13-0097**.

I agree not to discuss or disclose any of the content or personal information contained within the data, tapes, transcriptions or other research records with anyone other than the Principal Investigator, Megan Seaman, MS, the Co-Investigator, James Benshoff, Ph.D., or in the context of the research team. I agree to maintain confidentiality at all times and to abide by the [UNCG Policy and Procedure for Ethics](#) in Research and the [UNCG Policy on the Protection of Human Subjects in Research](#).

Date: 04/06/2013

Signature

Principal Investigator

To be completed by all members of the research team with access to personal data on human research participants.

File a copy with the PI.

APPENDIX F

BRACKETING THEMES FROM INDEPENDENT

REVIEW PROCESS – MAIN STUDY

Bracketing Themes

2-10-14

Things to be aware of when doing the analysis!

Researcher Themes:

- FAMILY RELATIONSHIPS: Interesting that in many stories I have heard anecdotally, one sibling seems to be implicated in the cause of issues – black sheep syndrome. Expression of empathy towards black sheep. Seems to be favorites – favored children, favored parents – goes back and forth. Attachments and old resentments from lost time or over spending of time. Generational – historical context. Roles - Recapitulate, rehash the same roles from family of origin; Family relationships is framework vs. Individual reality (intrapsychic); Safety net in family of origin vs. Safety in family of choice; Relationships with parents; Responsibility manifests from the closeness of the relationship vs. seeing family of origin/parents as a necessary part of life and then moved on; Open families vs. Closed families - Open to shifting vs. rigid roles
- SIBLINGS: Congruency in stories. Sib relationships vs. only child or not having support from sibs; Closeness of sibs vs. contention or not feeling connected (and no responsibility to feel connected); Only love and compassion vs. pain and resentment and rivalries
- CAREGIVING: End of life care – Death; Can't define life and death for another; Meant to change one person's life; Believe in reincarnation *Many Lives, Many Masters* –book by Brian L. Weiss, MD. Agreement to Care for family members and knowing roles (collective agreement) vs. primary care and sporadic involvement or dissociation – cutting off involvement; Dementia symptoms.
- SOCIAL INFLUENCES: Education - The less education, the less possibility; The more education, the more open. Gender roles.
- SOCIAL SUPPORT: Social support separate from Instrumental; Extended family connection; Supportive vs. Added pressure.

Independent Reviewer Themes:

- **IMPORTANCE OF THE FAMILY RELATIONSHIP:** I believe the family bonds are of crucial importance in an individual's life. These relationships provide a framework of how one interacts with other individuals outside of the family.
- **SIBLING RELATIONSHIPS IMPORTANT:** Growing up as an only child I have an idealized viewpoint of the sibling relationship. I believe the bond between siblings provides a constant support system in one's life. I have never experienced a close sibling relationship but I believe the close bond between siblings would provide ease in the care taking process.
- **AGREEMENT TO CARE:** Watching my mother and her siblings negotiating the proper steps to take care of their father who is suffering from dementia I am able to see first hand how important a unanimous understanding between siblings is in the care taking process.
- **EXTENDED FAMILY CONNECTION:** The extended family on my mom's side of the family is adding an extensive amount of pressure on my mom and her brothers to care for their father. The extended family is supportive but in a way that appears to be adding increased stress for my mom and her brothers all who live at least two hours from my grandfather.
- **DISCONNECTIONS BETWEEN SIBLINGS:** There is an evident disconnect between my mother and one of her siblings. Her youngest brother feels no responsibility for his father's care. This is causing strife between my mother and her youngest brother.
- **RELATIONSHIP WITH MOM:** Being an only child and having a strong relationship with my mom I know that I would do whatever I could to help make her life as easy as possible if she began to suffer from dementia.
- **SIBLING CONNECTIONS:** I believe that the sibling connections would be vital in the care of a parent who was suffering from dementia. If all the siblings are on the same page the care taking process would be a much smoother process.
- **PARENTAL FAVORITISM AND BOUNDARIES:** I have witnessed slight favoritism both on the side of my mother towards one parent over the other as well as favoritism of her parents on a specific child. I believe that favoritism can have a significant affect on the caretaking process. My mother's brother who feels no obligation to care for his father has a very caring relationship towards his mother and has been a pivotal figure in the care of his mother.
- **BIAS:** It appears evident that gender roles can become apparent in the care taking process. I have witnessed this in the dynamics between my mother, her siblings, and her

father. My mother has taken on the role of finding in house care. While she has taken on the role of finding the appropriate health care for my grandfather her brother has taken on the role of maintaining upkeep of the house and organizing maintenance type aspects of his daily living.

APPENDIX G
RECRUITMENT SCRIPT

Email and Phone Recruitment Scripts

Email Script:

Dear [Participant's Name],

Thank you for your interest in participating in my research project on adult siblings' perceptions and experiences of sibling connection and social support in relationships of siblings caring for aging parents with dementia. I have attached my recruitment letter (in word format or adobe acrobat format - whatever suits your needs) so that you can get an idea of the specifics about the project. But in a nutshell, the goal of the project is to gain understanding of your experiences and perceptions of the caregiving process for your parent. In particular, I hope to understand better the roles you play, the tasks you take on, who helps out, and triumphs and the challenges in the caregiving process. Please download and read the attached recruitment letter now.

In preparation for the data collection stage, I wanted to check in and see if you and your siblings would still be available to participate in separate interviews of the caregiving experience with your mom. If you and your siblings are still interested, then I wonder what your and your siblings' availability would be in the next few weeks. Each interview should take between 1-1.5 hours. That includes a brief demographic form and then the interview.

This study will take place at your residence or other private, secure, and confidential location of your choosing. Please let me know the address of where you would like to meet for the your private, secure, and confidential meeting, as well as details about the best way to get there.

Additionally, please let your siblings know to contact me with their interest in the study, so I can send them a formal recruitment letter and schedule time for their separate interviews. Let me know your schedule, thoughts, questions, and concerns. You can email me back at meganseaman@hotmail.com or call me at (216) 402-7372.

Thank you, [Participant's Name]! I look forward to hearing from you soon!

Sincerely,
Megan

Phone Script:

1. Introduction of Investigator or Research Assistant

Hello, is this [Participant's Name]?

- (confirm that I have the correct person)

Do you have a minute? My name is Megan Seaman.

I am a doctoral student at the University of North Carolina at Greensboro and I am working on a **research study** with my mentor Dr. James Benshoff.

You received information about this study in/ from _____ [describe how and when the participant received information about the study, e.g., my Uncle Greg, who works with you, a couple of weeks ago.].

2. Immediate opportunity to opt-out

I'm here to follow up on _____ [e.g., the conversation with my uncle, etc.) and to see if you are interested in hearing more about our study. Is it OK for me to continue?

- If individual says "no, not interested" = **stop, say "thank you for your time" but do not continue.**
- If he/she says yes, then continue or make plans to revisit at a more convenient time.

3. Make a BRIEF statement about why he/she was selected. Make sure the individual understands that this research is separate from his/her parent's clinical care. For example:

- Example: I'm approaching you to see if you'd like to be in the study. We are looking for sisters and brothers who are caregiving to a parent who has forms of dementia. This research is totally separate from the care that your parent is receiving and whether or not you decide to hear more about the research won't affect your parents' care.

4. Ask if he/she is interested in hearing more details.

So, are you interested in hearing some details about the research study?

- If not interested, thank the individual for his/ her time.
- If interested, then move to reading the recruitment letter.

5. After reading the recruitment letter, ask for questions, concerns, or needed clarifications.

What questions do you have at this time? What concerns you? What needs to be clarified?

- Clarify to the best of my ability.
- If not interested after learning more, then thank them for their time.
- If still interested, then ask about availability to meet for the interview

6. Ask about availability to meet for the interview.

In the next few weeks, what might be a good day and time to meet in your home for the interview?

- Schedule a time to meet for the 1-1.5 hour interview.

7. Get directions to interview location.

What is the address of where you live and what might be the best way to get there?

- If participants would prefer to meet in a different private, secure, safe, confidential, and distraction-free location, then ask for the address of that location and the best way to get there.

8. Exchange contact information (e.g., phone numbers and email addresses)

Just in case there are any changes that come up for either of us, let's exchange contact information. My phone number is (216) 402-7372 and my email address is meganseaman@hotmail.com . What is your phone number and email address that is best to contact you at? May I leave a message at your phone contact?

9. Ask participant to have siblings contact me for their interest in the research project

Please ask your siblings to contact me by phone or by email so that I may inform them about the study, answer their questions, and schedule their interviews. They can contact me at the same phone number and email address that I gave you before

10. End call

Thank you [Participant's Name]! I look forward to meeting with you soon!

APPENDIX H

DATA ANALYSIS INSTRUCTIONS FOR IPA

Data Analysis Instructions for Interpretive Phenomenological

Analysis (IPA):

Once the transcripts have been created, the data analysis begins. The analysis process is done one case at time. The researcher will begin the process from a stance of psychological phenomenological reduction, meaning that the experiences of individuals are taken exactly as they present themselves without assigning any interpretive meaning to them.

14 Steps

1. **Bracketing:** Giorgi and Giorgi (2003) suggested that bracketing be done as a means to ensure participants' experiences are taken as close to how they were accounted, and to bracket past knowledge so that researchers can look at the phenomena as if for the first time. Therefore, the researcher, as well as the independent reviewer, will participate in a bracketing exercise that consists of two parts.
 - a. **Part one** will require that the researcher and independent reviewer independently explore their expectations and biases about the study topic and write these reflections down.
 - b. **Part two** will require that they discuss together their expectations and biases about the study topic. In this way, the written and spoken awareness

of biases and expectations will be made clear and can be more easily bracketed to allow for a cleaner interpretation of the meaning making process.

2. **Reading Transcript:** The researcher will begin the data analysis by reading and rereading an entire transcript for one case (Giorgi & Giorgi, 2003; Smith & Osborn, 2007). This ensures that the researcher has a general sense of the transcript in its entirety.
3. **Meaning Units:** Then, the researcher will read through the transcript, while placing marks where a transition in meaning is apparent, thus creating meaning units (Giorgi & Giorgi, 2003). Smith and Osborn (2007) described a process of making comments of interest or significance in the left margin of the transcript at this step. In both approaches, the researcher keeps a mind of phenomenological reduction and participates in free imaginative variation to open to the possibilities of meaning for the respondent.
4. **Theme Titles:** Following that, and with the same phenomenological mindset, the researcher will transform the meaning units and/or comments of interest and significance into psychologically sensitive expressions or emerging theme titles (Giorgi & Giorgi, 2003; Smith & Osborn, 2007).
5. **Ordering Themes:** Once all meaning units and comments have been titled, themes will be ordered, first chronologically, and second according to analytical connections between themes or clustering of themes (Smith & Osborn, 2007).

- a. **Create a Table:** Subsequently, the researcher will produce a table of themes ordered in a consistent and logical way (Smith & Osborn, 2007).
 - b. **Superordinate Themes:** Clusters of themes are given titles that represent the superordinate themes. In the table, under each superordinate theme are listed all the themes that fall under that particular cluster.
 - c. **Identifying Themes:** Each theme that is listed has an identifier to aid in finding the original data in the transcript that is connected to the theme. The identifier is identified by the transcript identification code, page number, and line that the data are on. For instance, if a specific point comes from data found on the transcript SIB1 at page 14, line 5, the identifier would be “SIB1.14.5.”
6. **Independent Review:** Once this process is completed for the first transcript, the researcher and independent reviewer will convene to come to consensus on the themes found and superordinate themes that emerged.
7. **Next Sibling Transcript:** Once consensus is reached, the researcher repeats the process for other caregiving sibling transcripts for the other siblings in the family.
8. **Final Family Table:** Eventually a final table of superordinate themes is made for each family, with consensual analysis between the researcher and the independent reviewer.
9. **Independent Review of Sibling Transcripts:** After each set of family transcripts and analyses is completed, the independent reviewer will examine the data

analysis, results, and consensus of the researcher. Comments will be returned to the researcher and adjustments will be made accordingly.

10. **Next Sibling Set:** Then, the researcher moves on to the next family of siblings, each case to be examined for what it is.

11. **Final Table of Themes:** Once each family of siblings has been analyzed for themes, and final tables of themes have been made, then a large cross-analysis of themes will be made across families. In this final study table, themes will be selected based on two main criteria: 1) frequency that they appear in the cases, and 2) richness and how it illuminates other aspects of the phenomena under study (Smith & Osborn, 2007).

12. **Writing Results:** The final step in the data analysis process is writing up the results and final statement of meanings. In this step, the researcher translates themes into written narrative and reflections (Smith & Osborn, 2007). Here the emergent phenomena of caregiving siblings' experiences and perceptions of connection and social support are reflected upon and synthesized to provide a web of association between the different themes that arise and the actual reports of participants. Smith and Osborn (2007) recommended two different ways to present the narrative.

- a. **Results with Narrative:** One way is for researchers to present findings in conjunction with interpretive narrative and synthesis of previous research and future directions.

- b. **Results Section and Discussion Section:** An alternative approach is for researchers to present results with interpretive narrative in one section, and the synthesis of previous research with the study implications in another section.

13. **Depends on the Research:** Smith and Osborn further stated that determining which approach that the narrative process should take depends on the direction the analysis takes. Thus, as the translation and reflection process uncovers the meaning of themes that arise in caregiving siblings' responses, how the resulting information unfolds will determine whether the final step of writing up the results and narrative will be presented in one or two sections. Indeed Smith and Osborn clarified that "...when one sees the extracts again within the unfolding narrative, often one is prompted to extend the analytic commentary on them. This is consonant with the processual, creative feature of qualitative psychology" (p.76). Thus, true to phenomenological form, the essence of the study that emerges will indicate what form the results and their discussion will take.

14. **Limitations and Future Directions:** However, following the semi-structured method of IPA should allow for tentative systematic plan of action in observing the phenomena that emerge and making meaning from the superordinate themes.

APPENDIX I

UNCG INSTITUTIONAL REVIEW BOARD

APPROVAL EMAIL – PILOT STUDY AND MAIN STUDY

IRB Notice – Pilot Study

From: **IRB** (irbcorre@uncg.edu)
Sent: Fri 3/22/13 11:38 AM
To: meganseaman@hotmail.com
Cc: benshoff@uncg.edu

To: Megan Seaman
Counsel and Ed Development
1601 Olivewood Avenue, Lakewood, OH 44107
From: UNCG IRB
Date: 3/22/2013
RE: Notice of IRB Exemption

Exemption Category: 2.Survey, interview, public observation

Study #: 13-0097

Study Title: Caring for the Caregiver: Exploration of Social Support and Sibling Connection in Relationships of Adult Siblings Caring for Aging Parents with Dementia

This submission has been reviewed by the above IRB and was determined to be exempt from further review according to the regulatory category cited above under 45 CFR 46.101(b).

Study Description:

The study aims to understand the emergent phenomena of adult siblings' experiences and perceptions of social support and sibling connection in the task of caring for aging parents who have dementia. The researcher will recruit siblings through snowball sampling. Informed consent will be obtained and 90-minute recorded semi-structured interviews will be conducted for each sibling. Subsequently, recordings will be transcribed and analyzed through use of phenomenological inquiry. Finally, the results will be described, interpreted, and synthesized to establish relevance to families, formal care providers, counselors, and researchers interested in topic of siblings caring for parents with dementia.

Study Specific Details:

Your study is approved and is in compliance with federal regulations and UNCG IRB Policies. Please note that you will also need to remain in compliance with the university Access To and Data Retention Policy which can be found at http://policy.uncg.edu/research_data/.

Investigator's Responsibilities

Please be aware that any changes to your protocol must be reviewed by the IRB prior to being implemented. The IRB will maintain records for this study for three years from the date of the original determination of exempt status.

CC: James Benshoff, Counsel and Ed Development

IRB Notice – Main Study

From: **IRB** (ori@uncg.edu) You moved this message to its current location.
Sent: Tue 11/12/13 9:05 AM
To: meganseaman@hotmail.com
Cc: benshoff@uncg.edu

To: Megan Seaman
Counsel and Ed Development
1601 Olivewood Avenue, Lakewood, OH 44107

From: UNCG IRB

Date: 11/12/2013

RE: Notice of IRB Exemption (Modification)
Exemption Category: 2.Survey, interview, public observation
Study #: 13-0097
Study Title: Caring for the Caregiver: Exploration of Social Support and Sibling Connection in Relationships of Adult Siblings Caring for Aging Parents with Dementia

This submission has been reviewed by the IRB and was determined to be exempt from further review according to the regulatory category cited above under 45 CFR 46.101(b).

Study Description:

The study aims to understand the emergent phenomena of adult siblings' experiences and perceptions of social support and sibling connection in the task of caring for aging parents who have dementia. The researcher will recruit siblings through snowball sampling. Informed consent will be obtained and separate 120-minute recorded interviews will be conducted for sibling dyads in families. Subsequently, recordings will be transcribed and analyzed through use of phenomenological inquiry. Finally, the results will be described, interpreted, and synthesized to establish relevance to families, formal care providers, counselors, and researchers interested in topic of siblings caring for parents with dementia.

Modification Information:**Below is a list of the proposed modifications:**

Limit the study sample recruitment to 2 siblings per family and focus on primary caregiving siblings and one of their siblings who is willing to participate.

Expand recruitment to include sister-sister caregiving dyads and brother-brother caregiving dyads, as well as sister-brother.

Extend recruiting to community and health centers.

Include multiple possible formats for interviewing participants, such as face-to-face, phone, and video interviews.

Updated the recruitment materials and consent to reflect the changes

Investigator's Responsibilities

Please be aware that any changes to your protocol must be reviewed by the IRB prior to being implemented. Please utilize the most recent and approved version of your consent form/information sheet when enrolling participants. The IRB will maintain records for this study for three years from the date of the original determination of exempt status.

Signed letters, along with stamped copies of consent forms and other recruitment materials will be scanned to you in a separate email. Stamped consent forms must be used unless the IRB has given you approval to waive this requirement. Please notify the ORI office immediately if you have an issue with the stamped consents forms.

Please be aware that valid human subjects training for all members of research team need to be kept on file with the lead investigator. Please note that you will also need to remain in compliance with the university "Access To and Retention of Research Data" Policy which can be found at http://policy.uncg.edu/research_data/.

CC:

James Benshoff, Counsel and Ed Development

APPENDIX J

DEMOGRAPHIC QUESTIONNAIRE – MAIN STUDY DATA SUMMARY

Demographic Questionnaire
Main Study Results
Dec. 7, 2013 - Mar. 18, 2014

Questions	Dyad 1: Zoey (sister)	Dyad 1: Matthew (brother)	Dyad 2: Jim (brother)	Dyad 2: Bo (brother)	Dyad 3: Erika (sister)	Dyad 3: Patrick (brother)	Dyad 4: Stevie (sister)	Dyad 4: Mac (brother)	Dyad 5: Sharon (sister)	Dyad 5: Kevin (brother)
Race/Ethnicity	White	White	White	White	White	White	Asian	Native Hawaiian or Other Pacific Islander	White	White
Age (years)	62	64	66	62	64	56	47	48	54	44
Education Level	Master	Master	Ph.D.	Master	Bachelor	Bachelor	Master	Master	Bachelor	Bachelor
Employment	Self-Employed	Full-Time	Part-Time	Employed	Part-Time	Retired	Self-Employed	Full-Time	Part-Time	Full-Time
Hours	40	50	25	40	32	0	25	50	20	55
Relationship Status	Divorced	Divorced	Married	Married	Married	Married	Married	Married	Single	Divorced
Immediate Family Members (Names, Ages, Relation)	Zoey (62yo, self), Matthew (64.5yo, brother)	Zoey (62, sister); Matthew (64, self)	Elizabeth (63yo, wife); B.K. (30yo, son); L.K. (28yo, daughter); Jim (66yo, self)	G.K. (96yo, father); L.K. (54, Bo's wife); Reb.K. (29, Bo's daughter); S.K. (65, Bo's former wife/mother of R.K.); Jim (67, brother), R.K. (65, brother); Bo (62, self)	T.R. (67, husband); H.R. (35, daughter); A.R. (30, daughter); E.R. (27, daughter)	Wife; Patrick (56, self)	J.P. (44, husband); Car.P. (11, daughter); Chris.P. (9, daughter)	C.T. (44, wife); 7 children: T.T. (25, son), S.T. (23, daughter), R.T. (21, son), Joh.T. (19, son), J.T. (17, son), A.T. (15, daughter), C.T. (6, daughter)	Sharon (54, self)	Kevin (44, self); J.S. (16, son)
Family of Origin Members (Names, Ages, Relation)	M.E. (88yo, mom), L.E. (deceased, dad), Matthew (64.5yo, brother), Zoey (62yo, self)	M.E. (88yo, mom); L.E. (deceased, dad); Zoey (62, sister)	G.K. (95yo, father); B.K. (deceased, mother); R.K. (63yo, brother); Bo (61yo, brother); Jim (66yo, self)	G.K. (96, father); Jim (67, brother); R.K. (65, brother); Bo (62, self)	Mom (90yo); Dad (deceased); 4 children (I was the youngest; all 4 years apart): G.V. (68yo, brother), Erika (64yo, sister), K.V. (60yo, brother)	Mom (90yo); Dad (deceased); 4 children (I was the youngest; all 4 years apart): G.V. (68yo, brother), Erika (64yo, sister), K.V. (60yo, brother)	Mom (75); Dad (deceased); V.T. (49, brother); Mac (48, brother); M.T. (46, sister); G.T. (44, brother); R.T. (42, sister); L.T. (40, sister)	G.T. Senior (62, dad); Ja.T. (75, mom); V.T. (49, brother); Stevie (47, sister); M.T. (45, sister); G.T. (43, brother); R.T. (41, sister); L.T. (39, sister)	10 siblings: E.S. (59, sister), C.S. (58, brother), M.S. (56, brother), J.S. (53, brother), A.S. (50, sister), L.S. (48, sister), D.S. (45, brother), P.S. (43, brother), Je.S. (42, sister); Parents: E.S. (82, mother); Ja.S. (81, father)	Kevin (44, self-brother); Je.S. (42, sister); D.S. (46, brother); L.S. (47, sister); A.S. (49, sister); Ja.S. (51, brother); Sharon (54, sister); M.S. (55, brother); C.S. (57, brother); E.S. (59, sister) and Parents: Ji.S. (82, Dad); El.S. (82, brother)
Parent Gender	Female	Female	Male	Male	Female	Female	Female	Female	Male	Male

Parent Age (years)	88	88	95	96	90	90	75	75	81	82
Proximity to Parent	Within 6-20 miles	Within 6-20 miles	More than 100 miles	Within 21 -100 miles	Within 6-20 (currently); living with me (9 months ago)	Within 6 - 20 miles	More than 100 miles away (currently; Mom is in Manila, Philippines); within 5 miles (when she visits US; stays with Stevie)	More than 100 miles	Within 21 -100 miles	Within 21 -100 miles
Hours/week on Caregiving	4	2.5	1	4	24/7 (9 months ago)	4	Currently ?; When she visits, 24/7 (all day)	4	3	4
Types of Contact with Parent (Weekly)	Face-to-Face	Face-to-Face	Phone Calls; Face-to-Face	Phone calls; Face-to-Face	Face-to-Face	Face-to-Face	Phone calls; Face-to-Face; Text/email	Face-to-Face; Other - Skype	Phone calls; Face to Face; Textemail	Phone calls; Face to Face; Textemail
Frequency of Contact with Parent (Weekly)	1	1 - 2 visits	4-5 calls; 8 visits/year (every 6 weeks)	2 calls; 1 face-to face	1	1	?	0 currently	1 call; 1 face-to-face; 1 text/email	Per Month: 2 phone calls; 1 face visit; 4 textemail
Duration of Dementia Symptoms (Years/months)	5 years, 10 months (since Feb. 2008)	5 years	6 months	2 years - slight decline; 6 months - steeper decline	8 - 10 years	Approx. 6 years	1 year +	1.5	Approx. 4	Approx. 4.5
Duration of Caregiving for Parent (Years/months)	5 years, 10 months (since Feb. 2008)	3 years	5 years	7 - 8 years	3 years	6 years	12 years (since dad passed in 2002; but half the time she is in Manila)	1.5	Approx. 2	Approx. 4.5

Types of Caregiving Responsibilities (Weekly/Monthly)	Has clothes and labeled; respond to practical concerns; trying to help her stabilize emotionally	Visiting mother in dementia care facility; consulting with professional and caregiving staff; managing mother's financial affairs and real estate	Financial; Review medical appointments; Medication review and order; Mail sorting - junk mail; Emotional support and assist with decisions	Try to spend time with father on a regular basis. We do not like him driving at night, so on Sunday nights I provide transportation and have dinner with him (where he lives there is no provided meal on Sunday nights) Sometimes I have lunch with him also. communicate with brothers	9 months ago: Administering medications, daily glucose testing, doc. Appt., laundry, all meals, re-filing 12 different meds constantly, making sure she had activities (I.e., puzzles, crocheting, card playing)	Presently, I visit the assisted care facility and visit and check on her wellbeing with staff	When mom visits: Just being in her company. She is still able to function and care for herself. Preparing her meals and driving her around is what I do mostly for her.	Financial contribution towards mom's expenses; planning and decision-making with siblings	Visit my father once or twice a month at the nursing facility. Sit with him at dinner or take him to the activity room for bingo. Watch a movie with him or playing cards	Helping with finances (for Mom and Dad); budget mgmt (parents on a fixed income)
Type of Caregiving Involvement/Role	Has clothes and labeled; respond to practical concerns; trying to help her stabilize emotionally	Share responsibilities with sister: Visiting mother in dementia care facility; consulting with professional and caregiving staff; managing mother's financial affairs and real estate	Ongoing supportive engagement and ongoing pleasant relationship with dad. He is glad to have someone care for/about his needs.	Hang out/eat with him. Make sure eh is ok. Call him regularly. Put medicated cream on his back. Offer observations/suggestions to my brothers. Go to doc appts. With him if I can. Give feedback to my brothers when needed.	Presently, I take care of her finances (medical mutual, pharmacy and facility payments) and see that she has personal hygiene supplies	S/A/A; memory games and simple question/answers	As a daughter, just being patient with her repetitiveness and bouts of depression; monitoring her medication; coaching her into a positive state	Regularly with technology - almost everyday	My role is mostly supportive of my mom. I listen when she is having a hard time dealing with Dad's care, and try to help her resolve issues. I do visit Dad and take him to bingo and watch sports with him at least twice a month	Sporadic/competing with job and being a single parent

Family Members Who Support and Type of Support They Give (e.g., emotional, informational, and appraisal, and may include instrumental tasks)	Primary Support: Brother (emotional); Director/Nurse in formal care (emotional); Staff in formal care (ADLs, instrumental tasks); Brother, Sister, and Residential (formal care) support	Sister (emotional, informational, appraisal, instrumental); Friends (emotional and informational)	I receive support from both sibs and our spouses. The support is informational, instrumental, and emotional. Primarily from sibs as we are more active in caregiving than our spouses.	Jim has the most support	My 3 brothers would take her on Saturdays for the day (each would come once every 3 weeks). My husband cared for her when I was at work.	Primary support is with my sister who knows the most up to date info on mom's daily activities	My siblings, my aunts (mom's sisters), my husband who is a physician, other relatives, doctors	Mac's Wife (emotional support); Siblings (emotional, organizational, financial)	E.S. (emotional support); C.S. (emotional); Ja.S. (logistical support - helped with moving Dad to the facility, and will help with Dad when needed); L.S. (emotional support - will help when needed); P.S. (emotional support - will help when needed)	Sharon & Ja.S. (brother); Sharon (emotional and informational; most support; does the most out of everyone); Ja.S. (odds and ends for mom); E.S. (sister; keeping track of medications for dad);
Rate How Much Support Each Family Member Gives (Scale 1 - 10)	Brother = 10; Director/Nurse = 7; Staff = 9	Sister = 10; Friends = 5	Bo = 10; R.K. = 5; Susan (R.K.'s wife) = 5; Elizabeth (Jim's wife) = 10; L.K. (Bo's wife) = 5	Jim = 10; R.K. = 4	T.R. (husband) = 10+; Patrick = 9; G.V. = 7; K.V. = 3	Erika = 9	All siblings = 10; but we need to manage an overflow of support	Mac's Wife = 10; V.T. = 10; All sibs = 10	E.S. = 6; C.S. = 7; M.S. = 4; Ja.S. = 6; A.S. = 7; L.S. = 7; D.S. = 5; P.S. = 6; Je.S. = 4	Sharon = 8
Rate How Close You Are to Each Sibling (Scale 1 - 10)	Brother = 10	Sister = 10	Bo = 10; R.K. = 7	Jim = 10; R.K. = 3	Patrick = 9; G.V. = 9; K.V. = 3	G.V. (oldest bro) = 8; Erika (sis) = 6; K.V. (bro) = 0	All siblings = 10	V.T. = 10; Stevie = 10; M.T. = 9; G.T. = 9; R.T. = 8; L.T. = 8	E.S. = 10; C.S. = 1; L.S. = 7; = 9; M.S. = 7; Ja.S. = 8; A.S. = 10; L.S. = 10; D.S. = 7; P.S. = 9; Je.S. = 10	Je.S. = 3; D.S. = 1; L.S. = 7; A.S. = 5; Ja.S. = 5; Sharon = 9; M.S. = 1; C.S. = 7; E.S. = 5
Rate Perception of Siblings' Caregiving Involvement (Scale 1 - 10)	Brother = 10	Sister = 10	Bo = 10; R.K. = 5	Jim = 10; R.K. = 4	G.V. = 8; K.V. = 8; Patrick = 8	G.V. = 6; Erika = 9; K.V. = 0	All siblings = 10	All siblings = 10	E.S. = 7; C.S. = 6; M.S. = 4; Ja.S. = 6; A.S. = 6; L.S. = 6; D.S. = 4; P.S. = 6; Je.S. = 3	Je.S. = 2; Kevin (self) = 4; D.S. = 1; L.S. = 5; A.S. = 7; Ja.S. = 7; Sharon = 10; M.S. = 1; C.S. = 7; E.S. = 6

Hours Per Week Siblings Spend Caregiving (Name and Average Hours Per Week)										
	Self (sister) = 6; Brother = 5	Sister = 2.5	Bo = 2; R.K. = 2	I don't know, but would guess: Jim = 4; R.K. = 2	PAST: Patrick (would take mom overnight approx. once per month during 2nd & 3rd year she was with me); G.V. (would take her overnight occasionally during the 3rd year); Otherwise, K.V., G.V., and Patrick would take her to get her hair done, to lunch, and dinner	G.V. = 1; Erika = 2; K.V. = 0	?	G.T., R.T., L.T. = 1week/month; V.T., Mac, Stevie, M.T. = 4 hours/week	E.S. = 2; C.S. = 2; M.S. = 0; Ja.S. = 3; A.S. = 0; L.S. = 2; D.S. = 0; P.S. = 1; Je.S. = 0	Hours per Month: Je.S. = 5; Kevin (self) = 4; D.S. = 1; L.S. = 5; A.S. = 15; Ja.S. = 10; Sharon = 60; M.S. = 1; C.S. = 15; E.S. = 15

Describe Siblings' Caregiving Contributions (Name and Types of Contributions)	Matthew (brother): supports Zoey, negotiates larger business issues for mom, shares responsibilities - balance it out)	Share responsibilities with sister: Visiting mother in dementia care facility; consulting with professional and caregiving staff; managing mother's financial affairs and real estate	Bo (emotional social support, intellectual stimulation, share meals); R.K. (assist with laundry,shred documents, social support, share meals)	Jim (monitors financial information/medical/concerns of dad/legal); R.K. (his wife does dad's laundry/he occasionally takes dad out for dinner on Sunday nights/has dad for holiday meals/some legal	PAST: Patrick (would take mom overnight approx. once per month during 2nd & 3rd year she was with me); G.V. (would take her overnight during the 3rd year); Otherwise, K.V., G.V., and Patrick: would take her to get her hair done, to lunch, and dinner	G.V. (visits); Erika (visits; keeps up on situations in all aspects of care); K.V. (little or no assistance)	Take her to doctor; entertain her; drive her around; cheer her up	V.T., Stevie, M.T., and Mac (ideas for financial planning); G.T., R.T., and L.T. (ideas for financial planning; shelter; transportation; food; expenses)	E.S. (calls Sharon or Mom to ask how Dad is doing); C.S. (lives in Oregon; calls Mom to ask how Dad is doing); M.S. (no contribution); Ja.S. (visits Dad in the facility; also calls Mom to see how he is doing); A.S. (lives in Canada; calls Mom to check on Dad); L.S. (visits Dad every month); D.S. (lives in Seattle; calls Mom to check on Dad); P.S. (visits Dad in the facility, also calls Mom to check on Dad); Je.S. (no contribution)	Je.S. (emails/phone); Kevin (emails/phone/visits); D.S. (occasional calls); L.S. (emails/phone); A.S. (west coaster - emails/phones); Ja.S. (visits in person); Sharon (everything - emails/phones/visits); M.S. (emails); C.S. (west coaster - emails/phones); E.S. (emails/visits in person)
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Proximity of Siblings to Parent	Within 6-20 miles	12 miles	Bo (Primary is Providence, RI, 500 miles; Secondary is Richmond, IN, 50 miles); R.K. (2 - 3 miles)	Jim = 200 miles; R.K. = 3 miles	G.R. = 45 miles; K.R. = 25 miles; Patrick = 22 miles	G.V. = 50 minutes; Erika = 40 minutes; K.V. = 10 minutes; Patrick = about 20 minutes	My mom lives with my brother but alternates in stay with 4 other siblings: 50% in Manila (40% with brother, 10% with sister); 50% in USA/Vancouver (20% CA/LA, 20% Ohio, 10% Vancouver)	M.T., V.T., Mac, Stevie = 9 - 12 hours behind Mom in time zones; G.T, R.T., and L.T. = within 10 mile radius of mom	E.S. (20 miles); C.S. (out of state); M.S. (20 miles); Ja.S. (25 miles); A.S. (Out of Country); L.S. (30 miles); D.S. (out of state); P.S. (45 miles); Je.S. (15 miles)	Parents in Avon Lake, OH: Je.S. (12.3mi; Fairview Park); Kevin (self; 53.6mi; Kirtland); D.S. (out-of-state; Seattle, WA); L.S. (38.6mi; Macedonia); A.S. (out-of-country; Kamloops, BC, Canada); Sharon (23.8mi; Parma); Ja.S. (31.8mi; Bedford); M.S. (31.3; North Royalton); C.S. (out-of-state; Portland, OR); E.S. (19.8; Berea)
Perception of Siblings' Connections With You and Each Other	Primary connection in the world	Very connected	R.K. and Bo (friendly but somewhat cautious); R.K. (Good); Bo (excellent)	Jim (with me, excellent; with R.K., very good); R.K. (with me, OK or less than OK)	We are on good terms, although Patrick and K.V. are not speaking to each other since mom became ill	G.V. (relationship has dwindled quite a bit on every issue with mom); Erika has been a hero especially her husband. Since mom has had issues, K.V. has received 0 respect from me	Open, Transparent, supportive	Strong connections/interconnected	Overall, I think my connections with my siblings are good, although some are stronger than others. The connections between my siblings range from great to casual. Sometimes family gatherings are a challenge.	Good and bad; Connections with Kevin (D.S. moved too far away; disconnected and out of the loop); Connections with everyone (just depends; Je.S./L.S. do not get along with Ja.S.; Je.S. and M.S. do not get along; Je.S. gets along with everyone else; L.S. gets along with everybody)

Perception of Siblings' Social Support With You and Each Other	He's there for pretty much anything that I need. We have different emotional make up so had to negotiate some of those differences. He moved here from Cincinnati to help care for my mom. He's lived here about 2 years.	High level of support	Bo shares my (Jim) perceptions; R.K. may think it's better than I think it is; We are very comfortable expressing love and affection to each other	Jim = Excellent; R.K. = Fair	blank	G.V. and Erika - OK; K.V. not so much	Time zone makes it difficult but willingness is there. Sometimes not on the same page	Strong	Although we don't always get along, I think we would support and help each other when any of us were in trouble or needed assistance of any kind.	Social support is understated with all [siblings]; struggle with outward emotion - keep it to self
Others Involved in Caregiving	Brother; Staff at residential; Woman named Kathy (24hour care at home - primary care-taking lady) - she meets with mom 3x/week to have conversations	Professional and para-professional staff at Arden Courts (formal care facility)	Sister in law (R.K.'s wife) assists with laundry, social support, checks doc. Appts., will follow up with specific tasks I might ask	No one.	A caregiver would come every weekday for 2-3 hours to play cards with Mom during the 3rd year	My wife assists very often and always has	Family friend - neurologist; extended family	Mom's sisters and friends in Southeast Asia	Besides the nurses in the facility, there are no other family members or caregivers involved in the care of my father.	Nursing home = Avon Oaks

APPENDIX K

FIVE-FAMILY CROSS ANALYSIS TABLES

Five-Family Cross Analysis Tables

Table 1. Total (18) cross-family themes

Themes	Identifier	Excerpts
Individual Caregiver (Internal)		
1 Caregiving and Sibling Personality Differences (Individual)	MATTHEW.28.25-28.31; 10.25-10.28, 13.27-13.29	“she had a terrible time with our mom’s dementia – much worse than I did. I was just much more philosophical about it, and sorry to see it, and it’s sad, and discouraging, and so on and so on, and I wish it weren’t happening to my mom. But ironically what it meant to my sister, I believe, is that now she was never going to be able to get our mom to love her.” “At one time, I was much, much more aggravated and at times angry with [Mom] because she was so obstinate about not seeing what was so plain, right in front of your face.” “Um, but I tend to be more objective about it is what I’d say. I intellectualize it more than she does. I deal with it more on a more rational basis and she gets so wrought up about it.” MATTHEW
	ZOEY.30.14-30.15; 31.7-31.9; 36.12-36.15; 46.23; 38.2=38.4	
	JIM.28.16-28.19, 85.11-85.13, 58.8-58.12-58.13; 68.20-68.21; 11.20-11.23; 12.9-12.10	
	BO.15.4-15.6; 55.6-55.9; 55.11-55.22; 63.24-63.26; 13.24-13.30; 14.17-14.18; 28.22; 14.9-14.18; 22.12-22.14	
	STEVIE.37.5-37.8; 43.21-43.22; 13.18-13.29; 26.25-26.26; 27.7-27.28; 18.7-	
		“Oh, I have always experienced things on a more emotional level than he has. He has always struggled to understand what the big deal was.” “Now he said, “If she’s angry she’s angry. This is where she needs to be.” But when somebody is begging you to take her home.” “I don’t know what I would do. Because he maybe can’t get me emotionally, but he likes me... Right. And so it’s like we made our peace long time ago with the fact that we’re very different.” “Although, again, I would say, I’m an emotional wreck. And he would not.” “And I said to him, “we are different people. We are experiencing this in a different way. Your way is not better than mine, and my way is not better than yours. They are what they are. But do me the kindness of respecting my way.” ZOEY
		“My role besides emotional support and just you know talking to him pretty often during the week is uhh making sure the finances, all the taxes, basically any and some medication stuff but just the financial stuff making sure that his investments and his social security.” “Yeah Bo will do pretty much everything I will do except for the financial things because that’s what I’m doing” “Yeah yeah yeah and you know [Rbrother] will go over and empty the trash bags and make sure the stuff is and make sure the stuff gets shredded and he’ll pick up laundry and take laundry back.. Its instrumental, exactly, and I don’t know

	<p>18.13</p> <p>MAC.23.12-23.17; 40.8-40.10; 41.12;- 41.19; 43.16-43.18; 46.8-46.10; 70.24- 70.26</p> <p>ERIKA.1.14; 1.25; 1.36; 2.1; 3.28 - 3.34; 4.3 - 4.9 4.14- 4.22; 17.8-17.17; 17.19-17.21; 18.15 - 18.16; 18.20 - 18.27; 19.23 -19.24; 20.12 - 20.15; 20.30 -20.31; 22.5 -22.11; 32.1; 38.5 -38.12; 40.24 - 40.32; 41.1 - 41.7; 46.24 -46.27; 47.11 -47.13</p> <p>PATRICK.3.16; 9.28; 4.9 -4.10; 5.18; 6.5 -6.6; 12.4 - 12.7; 14.23 -14.25; 4.22 - 4.23; 6.32 - 6.34; 10.9; 11.3 - 11.16; 12.3 -12.4; 2.12 - 2.32; 3.7 - 3.9; 5.21 -5.24; 6.9 - 6.11; 7.4 -7.8; 9.15 - 9.17; 10.4 -10.9; 27.5 -27.7; 27.11 - 27.12; 2.3; 3.6 - 3.7; 7.2; 22.22 -22.25; 27.26</p> <p>SHARON.7.9-7.10; 10.4-10.5; 12.4; 16.1-16.3; 25.9-</p>	<p>qualitatively day-to-day what happens” “No and it wouldn’t... there is no... the emotion, if there is any emotional valence to it, it would be more of disappointment or sadness” “And and we have a very similar, my brother Bo and I have a very similar worldview and perceptual aesthetic... My brother RBrother is very concrete.” “So that that’s a difference in the communication, a difference in the emotional connectedness and the kind of richness of the relationship.” JIM</p> <p>“I mean I call him or I go over. He appreciates phone calls and yeah all that. He always enjoys me coming over and it’s a good thing. I have a really good relationship with him” “So Jim and I talk regularly pretty much and he appreciates to at least have me to bounce ideas off or at least to vent but I mean we can talk, we have the same concerns and he’s sort of more in it because he’s viewing the financial, he’s got his hands in the financial stuff “ “Yeah it was sort of delegated to [Jim] but as yeah it’s his baby ... He’s the eldest child and some how my parents... I mean its really weird because they set up this thing in Florida in the wills and the trust whatever it is... Yeah and trusts or whatever and I’m just like umm... I remember at one point it was like because my parents have always tried to do things very evenly but then all of a sudden it was like there was after my mom passed away she had a trust but it was Jim and RBrother and I wasn’t on it. I was like well whatever” “Jim and I are both sensitive to the fact that they do live there and they do do things and they are there and I will say sometimes Rbrother’s wife will go to the doctor or RBrother’s supposed to or sometime RBrother goes to dad.” “. Jim, my oldest brother, you know we were all sort of involved but Jim particularly because my dad seems to, since Jim is the eldest, he seems to fall in line with the most of my father. I mean they apparently have a very good relationship and my father at this point anyway looks to my brother for advice or would rather give him things to do. I mean since my mom is not there, I mean my mom really provided a lot of support for him” “I mean [Dad] will talk to us individually or as a group has the same message basically” “. So we would like we would have these summits is what I called them. I’d have minutes and I’d have me laptop” “I: But you aid, so you guys are all sort of involved in that since your mom passed away but your but it seems like Jim your dad kind of defers to him. B: Well he does but no I I think that is more a recent thing but he always has to some degree” “I mean he will talk to us individually or as a group has the same message basically” “Oh yeah but the point is that when one has the opportunity to move on I chose to move on and I guess if we are talking about siblings here, [Rbrother] just chose to stay put and do the sort of more conservative thing and just do what he’s been doing” BO</p> <p>“So it is just a matter of just setting things into place and I don’t want to be boss about it so I am just being tongue and cheek about the whole thing. I am older than some of them and I just feel like you know like lets just not make this a new issue. The issue is mom not just getting on the call.” “I’ve never seen that side of me but I notice I am being more and more impatient with her and my husband has to say ‘gosh why are you so impatient with your mom?’” “We are trying all these things: ignore, get mad at her, tell her to change the topic we don’t want to hear it. My brother Mac is different he says like ‘why don’t</p>
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		<p>"Well, as I may have explained to you. I cared for my mom in our home for three years" "my brothers go on different days of the week... They're all retired.... I'm working part-time. I work four days a week and Thursday is my family day" "so presently I'm not caring for her other than visiting her at the facility" "Okay well I pay all of her bills. When I visit, I have to take her personal hygiene supplies. I have to take her depends, toothpaste. Wipes and all that kind of thing." "Oh, compared to what I was doing, it's nothing." "I did work and I would have to get her up in the morning. Check her blood. Do the breakfast. Empty the commode. Get her dressed. Um feed her" "And Patrick lived the closest. So I would say Patrick probably visited her more often. And if there was an issue like the one sugar dropping, you know he was there. But I mean Patrick is .. Being a policeman, he was more aware working with paramedics.... The others really didn't really have a clue about that. And they didn't know how to test her blood sugar. They weren't involved in her like healthcare ... They would just come and visit with her a little bit. Cut the grass" "Um so um when my mom came here I remember KBrother saying something to me like well. He implied it was just a given. Well of course she would.." "And so what happened was Patrick got very annoyed with my other two brothers and this is how the dynamic affected our family. He wrote an email to my two brothers and said I think the two of you need to step up and there is no reason why you can't take mom overnight. Erika and My Husband need a break. And KBrother got totally, totally angry." "You know, I really don't know because we don't ask each other. You know did you go this week. Because it doesn't matter to me. But I can tell by emails that they go. I don't know if they go every week or if they go every other week but they go on some sort of regular basis." "Um but if I have something, you know, crucial to ask them or tell them, it goes to all three. You know... Yeah, yeah.. so yeah you know, we talk about changes. You know GBrother noticed one of her legs swollen after she had been in the wheelchair for a while. And so I didn't .. I didn't notice it but GBrother did. So you know we had the nurse look at it. So things like that. So we .. you know we talk and we share what we see."</p> <p>ERIKA</p> <p>"Kbrother is in Broadview Heights. 20 minutes [from mom]" "so me and Kbrother are close [to mom]" "then Gbrother took over. He made the schedule and we would take turns picking her up so my sister would get like a day off." "Now we stepped up to the plate more than my oldest brother and Kbrother." "Their excuses were... Gbrother, 'well I don't have a bedroom on the first floor" "The first time Gbrother took her over on a weekend the first time he took her my mom cried the whole time. And he took her back to my sister and my sister told me." "And you know [Kbrother] would come pick her up at 11 in the morning and drop her off at four or five because he had plans that night and I kept hearing this..." "Kbrother helped out" "No he picked her up and took her to his house during the day, drove back there at night, and did what he had to do. He slept on the couch in the living room. My sister thought it was so bizarre. in the morning he would leave and take her back to his house because he had her for two days. This is what he did for the two days. What I think what he did because he could do stuff at his house and just prop her in the chair." "I'm like how come you can't take her for a weekend? 'It doesn't work it</p>
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		<p>doesn't work.' " "so when we had these periods... you know my sister would call her and she's not sounding right can you go over there and then the one time you know we called emergency to come over and she went to the hospital and it just declined from there." "I was the closest so it was easy for me to swing by there. I probably went over there more often for a period because I was so close." "so we were the first ones to say, okay I'm going to pick her up on Friday night and bring her back Sunday." "We put her in this backroom over here, it is like a guest room, it used to be our garage and kind of have our guest room. We got her a bathroom and go down the steps and empty it and everything." "And I think the first weekend we took her was... it coincided with a baby shower for Erika's daughter-H I think... I think that was the first weekend it just...Yeah it's just like let's just take her and get her out of your hair for the weekend. It was one of the first weekends." "With her really umm... but you know I make sure she is okay, we talk, go to lunch. It's a routine we used to have we would go pick her up, take her to get her hair done, and go out to lunch. It was like the thing we always did." "Because I went to go play cards with her" "So you know and my sister had her in her house for over three years and because she was living by herself." "And they never like they would be stuck they couldn't go anywhere." "Right and you've got your own little room and you've got Erika takes care of you. Her cooking because of the diet my sister she knows what she is doing. If you have the right diet you don't have to hardly check your blood sugar." R: "So what kind of medications is she taking?" P: "I have a list somewhere. I mean Erika is more on top of that." PATRICK</p> <p>"When did [mom] really start taking over? Umm...it's been a couple of years. Probably 3 or 4 years" "So [Mom] just started keeping more of an eye on him and as the months progressed " "So she took care of him, made sure he changed his clothes, made sure that he ate" "Yeah, that's a huge job. It's too much for us... Yeah and it's also dealing with the separation. Between, I'm too close to it ..." "[Jsister's] the youngest. She, I don't think she's come to terms with it. She's never gone to see him.. She just doesn't want to see him in there.." "And Esister, I think Esister is another one who really hasn't come to grips with it ... So she didn't want to do this because she didn't want to talk about it" "[Cbrother] got some real good insight into dad's situation... He's pretty, I think he struggles with things being so far away.. So he's, but he's willing to talk thru just about anything that's going on" "yes. He's a little distant from it. He doesn't really reach out to see how he's doing. If we were to call and say, "Dad's having problems. Can you come?" He will. But he doesn't, he doesn't talk to mom that much. He's kind of, you know, it's like he got there and he didn't really come home for about 8 years to visit..." "Yeah, he was in the dog house for a long time ... Then he finally came out a couple years ago with his twin boys and his wife. So all is good now. But for a long time it was just kind of..." "And Kevin... He's the second from, he's the second youngest ... He lives in Kirtland. So he's way far out, away from Avon ... He's fifty miles away. So he doesn't get out this way much. But he is, he is connected. He does call my mom and see how she's doing. He does call me. He asks me how Dad's doing. "Do you need me to come out? Is everything okay? Do you need anything?" I can call him and talk to him about it." "[Mbrother] is ah, well, he's a good big</p>
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		<p>brother. If I need him for something, needed something or needed help or had a flat tire, I'd just call him. That part is good. I can talk about that part. But as far as personal things, emotional things, he just doesn't, he's just not..." "And [Mbrother] loyal and he's kind. And he's trust worthy, all those things. He's very, when it comes to family outings, he becomes withdrawn. He kind of doesn't really get into the mix of the conversation or anything. He doesn't really stay very long. So he's kind of there, he's on the periphery so" "And I remember asking [Mbrother] at one of them, 'what do you think about this?' 'What do you think about us moving Dad to the VA home? What do you think?' He said, 'Well, whatever Mom thinks we should do, that's what we should do.' Just..." "Yeah. I mean I'm there the most. Because I go every weekend to see her.... I go every other week to see him... I'm in the habit of going" "We'll sit and watch that. Sometimes I'll bring cards and we'll play a game. Or I usually bring jelly beans cause he likes jelly beans" "As any of us listen to mom when she has troubles..." "My Mom, she's his executor. She's his contact. She's his advocate" "Yeah, in fact, my brother is the executor of her estate. I think I'm the second on the billing or something. Yeah. Me and my brother Kevin I think" SHARON</p> <p>"because I didn't see him everyday. You would notice things if you would see someone everyday. So, that looks a little different.. As opposed to being with him everyday. You don't really notice the gradual shift" "[My siblings] not necessarily doing a whole lot of care giving." "That's a lot of hours, so.... Really, it's fallen to me no so much. I'm more of a.... I get out there when I can... So, there's nothing I'm doing specifically at this point in time for my dad. I'm helping my mom. Yeah. So, I'm not so much doing a lot for my dad. I'm helping my mom with her finances. Um, just with odds and ends. And, even that, being Kirtland, and her in Avon Lake. That's hard to do. So, I don't have a direct responsibility... Once a month" "Uh, finances, and then doing odds and ends around the house... It's helping her with the budget" "I'm, right now I'm just sporadic .. Yeah, because, my job is nuts" "Out of all the siblings. She does, and then Jbrother. You know, Jbrother works hard at it.... Sharon does a lot. She's out there every weekend. She's the one whose the key person right now. And, uh, Jbrother is too. He does a lot of the odds and ends for my mom. Um, yeah, Esister was doing a lot in helping to manage my dads meds – keeping track of them – before he went to the nursing home." "[Caregiving of siblings] Not anything significant that I'm aware of." "Um, Mbrother is pretty much disconnected. He knows what's going on, but he doesn't really want any part of it." "And, Dbrother is.... Yeah, he's, he's completely disconnected." "She, she's um..... she's very vocal about, um.... And I can't tell if she's against it or for it, but she was against it at first, but she has a lot of fears of his care – of making sure he's being taking care of OK. And that just overwhelms her. The thought of my dad in a nursing home is overwhelming to her" "She has the ability to do it because she's not married, and so there's no... not married no kids, so it gives her the ability to have the time." KEVIN</p>
2 Active Full Lives/Doings in	MATTHEW.1.18-1.23, 2.2-2.6, 2.11	"Um, I work fulltime... I have a somewhat active extracurricular life, so that I have evening meetings, sometimes work meetings, some committee or board meetings. I referee soccer....So I've got a pretty full

<p>the World (Microsystem)</p>	<p>JIM.3.3-3.10; 4.4-4.5, 4.15, 5.13-5.15, 5.23-5.24; 8.8; 9.8</p> <p>BO.3.1-3.27; 4.9-4.12; 5.12-5.17; 6.8-6.10</p> <p>STEVIE.1.15-1.29</p> <p>MAC.14.11-14.25; 15.12; 22.11-22.12</p> <p>ERIKA. 1.18; 1.25 - 1.26; 2.3; 4.9 - 4.13; 4.22 - 4.25; 5.1 - 5.32; 6.1 - 6.34, 7.1 - 7.8; 7.10 - 7.29; 7.29- 7.32; 8.1 -8.2</p> <p>PATRICK. 8.11 - 8.24; 20.23 -20.25; 33.2 -33.9; 58.1 - 58.27; 59.1 -59.29; 60.19</p> <p>SHARON.19.19-19.24; 20.1-20.6; 21.5-21.9; 22.1-22.10</p> <p>KEVIN.13.21-13.26; 47.17-47.24; 48.12-48.13; 48.21-48.23; 49.1-49.3</p>	<p>life I think” MATTHEW</p> <p>“What I’m doing in the world?” “Umm... I go to work. I get up and go to work umm... 3 to 4 days a week... I am sort of in this retirement glide.” “And I have a lot of active things that I have always done that its really simply a rebalancing of how much I do of what.” “Yeah I function as a, I’m a geriatric psychologist” “So that’s what I do and then I also play a lot of music so... umm, I work with a number of groups and umm... so when I am not at work and not dealing with my wife.” “I have a real, my real band the one I’ve been with has been 16 years with this particular group and then I work with a number of singer songwriters.” “So, I’ve got my fingers in a lot of stuff. “ “And when I’m not doing that I’m really sort of taking care of my dad.” JIM</p> <p>“What do I do? I either go to the office and do some work on the computer and deal with that downtown umm or I will work with various trades people to push my... our projects forward...yeah I’ve been involved in the jewelry business, I was involved in the watch business so I grew up in the retail business. Umm... I’m a gemologist. I got involved from there, I got involved in the watch business on a wholesale level so then I lived in New York, I traveled to the far east, I ended up living in Hong Kong and running stuff over there for stuff here, and then I was hired by a company here and I was in charge of the watch division. Excuse me not here in Rhode Island, in Providence, Calibri...” “So the dollar for dollar where we are here in Richmond is stretched so I started thinking about that so then I started taking money out of my retirement fund to do this but I have always enjoyed real estate I have just never had the opportunity to get my hands dirty or to get involved” “No she still works, she’s in Newport, she lives in Rhode Island. We have two properties there and she works for Reebok and she runs for more than 10-12 years she’s the manager of the store in New Port... Not enough and I go back and forth as need be so also one of the things I do in the morning is deal with emails but I also have a video production business” “Right so I’m and its tough because I’m pretty focused one way and I, its like okay I doing this now, the house thing, and I’ll do the video thing when I’m there and its hard to have both hats on” BO</p> <p>“first of all I have two young children, 11 and 9 and basically get up really early, get them ready, prepare their lunch, drive them to school. As soon as they are in school, I have a private practice, a life coaching practice.. Yeah so I umm as soon as I am back here I either work in my study or meet the client in my study or meet my client outside.. Yeah so the whole time, its hard when you are working from home, that whole time is inundated with work that I do as a life coach or career coach and in between are of course family duties chores. It is kind of hard to separate them.. Its very hard and you know I know we are talking about my mom eventually but when my mom comes it gets even harder because now I am juggling, serving three different entities like my kids and my mom is a guest and my work. It is hard to insert my work in there so” STEVIE</p>
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		<p>"I wake up at six, I live right there.. I go home 6:30 typically and have dinner with the kids as opposed to many years of working downtown, odd hours, working on Sundays, 3 shifts straight sometimes... A day in the life for me is really hitting that grind everyday and coming home... So six o'clock I wake up. I help with the kids. Sometimes I make breakfast. Sometimes I eat the breakfast somebody made for me. Then in the household I have two kids who are in high school, one in kindergarten" "I have 7. I have... one is a, it's a long story." "Yeah and when my mom comes to visit it gives me time to spend with her too. I come home and she is there. I have dinner with her and stuff like that" MAC</p> <p>"Morning that this and then I would go to work and then I would come home at noon." "No. I'm working part-time. I work four days a week and Thursday is my family day. So." "But you know it's not that I love, love, love the work it's just that I'm not 65 yet and you know I get health insurance through that company so I'm kind of hanging in there. You know 9:00 to .. 9 to 5. Four days... Um well we have .. we grow vegetables and flowers for the farmer's market. So like right now the seeds are coming in. Shortly he'll be planting seeds downstairs under the grow lights and so. So I do that with my husband and my two daughters. I also have like a sewing business so in the evenings and weekends I sew for people." "So it's a very tedious thing and actually I have a magnifying lamp that's over there behind the chair. It's usually sitting right here. And I just you know I do this hand darning and um she said to me, if you don't mind doing this she said, I could keep you busy the rest of your life." "I could do it 8 hours a day but it's just too hard to do eight hours a day. Maybe 3 or 4 is tops." "It's a really. It's a really .. it's a ... I think it just was divine intervention that we connected. Because I love to do it and she is patient." "Maybe and I think patience." ERIKA</p> <p>"No mom we've been married for since 1993, I have a granddaughter, and my daughter's 30 years old..." R: and " a police officer for 20-30 years" "Gbrother you know when I was working at CMHA because I had a Monday through Friday job primarily. I was sailing with him he still races today." "Well like this morning I woke up, went to the gym so I was there for an hour and half. If it was warmer out I have to clean out the garage I have projects I want to work on woodworking things. Well I got some molding I have to redo. The dogs chewed up a couple of pieces of molding I have to fix and umm... I want to I have a lot of projects I have stuff in the garage I have to work on its going to be for the campsite." "I was a big skier but umm... I just decided I skied a couple of weeks ago and I decided I'm done. My back and my shoulders....yoga.. It was one of the hardest things I ever did. Yeah, it was yoga for men class. The instructor was like this fast boom go to the next thing go to the next thing." "I'm a cyclist in the summer so I kind of cross over" PATRICK</p> <p>"My world...ahhh...well...(pause) Work, well, I work at Southwest General in the gift shop. I'm the assistant buyer there... And recently my job was downsized to half-time, twenty hours a week, which sucks... so...I'm looking for a new job" "So it's been when I'm not working, when I leave work, I go</p>
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		<p>home and go online and look for a job... Well, I'd like to stay in retail with the buying background"</p> <p>"Well, umm, I'm trying to run my 5-K, I train... It's a sickness. (laughter)" "So I go to the Y at least 3 or 4 times a week ... I get some treadmill running in and in the spring, I'll go out to the park and run there. So I do that and I do a jewelry line on the side ... It's mine, it's just something different to do" SHARON</p> <p>"I'm in finance. Research and development, finance at Nestle. .. And, then taking care of Pson.. I'm a single dad. And, the commuting back and forth from Kirtland to Solon is 24 miles, which isn't a whole lot of time and energy to put towards that." "I wake up at 5:30, get myself together, get Pson out the door to school, get to work about 7/730, some days it's about a 10 hour day. Come home, it's there 25 minutes of drive time one way and 25 minutes the other. I come home tired and uh get Pson some dinner. He's with me part of the time. He's with his mom half the time and he's with me half the time... In Willowick. Which is close to us. Get him going and then take care of the dog. Make sure he's all happy and everything" "Yeah, and I have a girlfriend, and she has 3 young kids. She's actually a widow. Her kids are 7, 5, and 3.. No. Yeah, so when I'm not spending time with Pson. I'm not at work. I'm not with Pson, um, I very little down time. Because I'm doing things with her and for the kids. In fact tomorrow night I'm watching the kids cause she has a board meeting to go to. She's ... a veterinarian. She does surgeries. She does work for a non-profit. She's busy. SO, uh, between work, and Pson, and spending time with my girlfriend and her kids, there's not much left there" KEVIN</p>
3 Competing Obligations (Microsystem)	<p>MATTHEW.5.7-5.12</p> <p>ZOEY.20.11-20.12; 21.10-21.22, 21.24-21.25</p> <p>JIM.39.3-39.8; 72.4-72.14; 48.20-48.21; 49.1-49.3; 57.25; 58.2-58.6</p> <p>BO.20.10-20.12; 53.29-53.30; 60.7-60.24</p> <p>STEVIE.1.15-1.29; 36.30-36.33; 20.20-20.24; 36.30-36.33</p>	<p>"cause I was in Chicago, and she was in Cleveland, and she was doing all the heavy lifting. I mean I was coming to Cleveland quite often... 'cause I was, you know, 375 miles away in Chicago..." MATTHEW</p> <p>"The woman that my brother married, um – this is not clinical – was nuts! .. She was very jealous of my relationship with my brother [Fraggle whimpers]. And that has to do with her family history." "And so he kept me at a distance and he deferred to his loony wife who would interpret things so crazily that I was like "who is this man?" And he sounded different. He was impenetrable. Ok. Since I'm telling stories, he lived in Chicago... And the one day the telephone rang and [Fraggle cries] and in his voice it was my brother... My real brother. He separated from His wife and there he was. And now I will say, he also went back to that marriage, which was so stupid... But she, I'm not exaggerating, she systematically offed all of his close friends... She could not tolerate. And I wouldn't let go. My image is I'm hanging on and she's got a hatchet [laughing]" ZOEY</p> <p>"Umm, so they had a family occasion. It might have been a 50th anniversary or a 60th anniversary something in Florida. We're all there, we're all in Springfield doing something and so over time uhh... things got better. He divorced his wife; I don't know what that was ... Well yeah it could but it gave us the opportunity to do things differently" "I just wish I just wish that I could be there more and sort of do more. That's the part that is the hardest... Yeah, if the weather were good I would have been down there,</p>

	<p>MAC.46.2; 47.1-47.3</p> <p>ERIKA.18.7 -18.9; 20.26 - 20.28; 1.18; 1.25 - 1.26; 2.3; 4.9 - 4.13; 4.22 - 4.25</p> <p>PATRICK.13.15-13.16; 13.23 -13.28; 14.14 -14.15; 21.26 -21.27; 22.7 -22.8; 3.14; 3.19; 9.28; 13.2 - 13.4; 14.4 - 14.19; 18.32; 19.2 - 19.4</p> <p>SHARON.2.7-2.11; 2.19-2.20; 29.7-29.14; 30.15-30.17; 38.9-38.11; 38.17-38.24; 40.1-40.19; 53.13-53.15</p> <p>KEVIN.4.3; 13.17-13.19; 16.19-16.25; 29.2-29.8</p>	<p>the last time I was down there was in November... And then of course there are times I am performing on the weekends too so that” “I: Does [your wife] ever go down? J: No, umm... it’s too hard with the dogs” “Yeah and that’s not easy because you know when the weather’s good I try to get down there once a month, every 6 weeks. When the weather’s not so good its like he says, ‘when are you coming down here again?’ I said, ‘you know I can’t’” “Well, I think that [Rbrother] is influenced by his wife about...” “lots of stuff and then he sort of and then that may be part of it. He is saying something that she would say but then he’s not sure of all the reasons why she would say it... Yeah, a lot of times he is the messenger, exactly. So umm...” JIM</p> <p>“Yes and so that just dissolved into a really horrible situation especially because my parents wanted to get out of the business and then spouses came into it, for both of us and it just got really ugly and everything imploded” “my sister-in-law, RBrother’s wife, does do my father’s laundry so there is a connection there begrudgingly or not there is a connection” “Yeah and [Rbrother’s wife] Susan’s saying... yeah I think she pretty much runs the show there well actually their son runs the show... So when Jim is there I try to make sure I am there because it is good that we are all together and then sometimes we’ll pull RBrother in... It often it seems like reluctantly he will come.. Oh he’ll be there you know he’ll be there for meals and things but often times we’ll want to hang out for an hour or two after we eat to talk about things and he might be off doing something, be at work, or whatever he does... Which I don’t know we don’t know what it is” BO</p> <p>“first of all I have two young children, 11 and 9 and basically get up really early, get them ready, prepare their lunch, drive them to school. As soon as they are in school, I have a private practice, a life coaching practice.. Yeah so I umm as soon as I am back here I either work in my study or meet the client in my study or meet my client outside.. Yeah so the whole time, its hard when you are working from home, that whole time is inundated with work that I do as a life coach or career coach and in between are of course family duties chores. It is kind of hard to separate them.. Its very hard and you know I know we are talking about my mom eventually but when my mom comes it gets even harder because now I am juggling, serving three different entities like my kids and my mom is a guest and my work. It is hard to insert my work in there so” “Yeah the time zones like just we are all in different stages in our lives. Like my brother’s younger children, mine are middle school, some are in college just our plates are full in general so but yet each one has to carve out that time to care for mom so umm” “In fact if there is ever a potential conflict it is our closeness verses the sisters of my mom. Sometimes they try to take to matters in their own hands where as like okay we have to get our act together because auntie is, they have a strong personality so they have a way of like this is our sister but this is our mom” “Like my brother’s younger children, mine are middle school, some are in college just our plates are full in general so but yet each one has to carve out that time to care for mom so umm” STEVIE</p>
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		<p>"In a way I sense it that my mother might be getting in the way of his lifestyle now." "said 'you know what I like don't get me wrong' Rsister was not involved in this conversation. I mean I went to school with the guy so I like the guy [Rsister's husband] but I think he is just tolerating mom at this point he wants to have his life" MAC</p> <p>"Yeah and Gwife has a mother who is the same age who is not mentally impaired and you know still drives. She's 93 and still drives. But Gwife still you know takes good care of her mom and so she couldn't you know dive in nor was she expected to but she knew that the brothers, my brothers needed to step up" "Morning that this and then I would go to work and then I would come home at noon." "No. I'm working part-time. I work four days a week and Thursday is my family day. So." "But you know it's not that I love, love, love the work it's just that I'm not 65 yet and you know I get health insurance through that company so I'm kind of hanging in there. You know 9:00 to .. 9 to 5. Four days" ERIKA</p> <p>"I think a lot has to do with their wives now. Kbrother and Kwife, Kwife's parents her father got had a stroke and it totally incapacitated him. Mentally, he didn't know what was up. Yeah so he (Kbrother)... I heard the story all the time that he had to spend over with her parents and then it was her mother taking care of Joe, the stress on her, he was always over there doing stuff and then he got bad where he had to have diapers before he went to the nursing home." "So I think you know Kwife was an obstacle for him and I think Gbrother and Gwife, I think Gwife...Gbrother yeah and I think as far as mom spending the night over there I think Gwife was more of an obstacle than probably Gbrother was." "Yeah but I don't think... I think it is just a gut feeling that I have that Gwife must be more of an obstacle there than I think Gbrother would be." "Speaking of the wives and everything but for whatever reason especially my mom and Erika's Husband never seemed to hit is off." "I... s she just... I don't know the exact wording but she just let it out there and which obviously made the situation even more uncomfortable for everybody." "Gbrother, the oldest one, he is in Elyria" "Gbrother's far away" "He's busy; he is involved in all kinds of things. Time is limited now he is retired but before that he was working a lot of hours with the company and I think a lot has to do with their wives now." "Well her father died years ago and her mother is still active and drives. She is in assisted living but she is very self-sufficient. Umm... so they don't have to do a whole lot with her. I'm sure they do run her to appointments and assist her but she can get around, she's sharp mentally. She's up there she's probably in her late 80s." "So Gbrother's real talented because he went to school for engineering originally." "Umm... first he was a teacher and then he didn't like teaching. His wife Gwife is a teacher. He didn't like that and ended up going into engineering sort of field so he is pretty handy with figuring out stuff." PATRICK</p> <p>"My brother has two adopted daughters.....in Oregon. My other brother in Seattle has twin boys.....my sister in Canada doesn't have any kids but she's a stepmom to two... I: Do you have kids?... S: No" "I think [Dbrother] just wanted to escape the big family.. Well, he went to school there. He went to U.</p>
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		<p>(Dub?) Found a girl friend and he stayed and found a wife and a life. I don't get. I didn't really understand it for a long time. Now I do. Now that I'm older. Now that I have things going on. That's his thing. That's his life." "[Kevin's] fifty miles away. So he doesn't get out this way much" "So we lived together for 4 years. And we had a really good relationship, I think. And then he met his wife and then things just changed. Now I feel like I'm kind of out, on the outskirts of that..." "It was hard to maintain a relationship so with him, it was really hard to maintain a relationship because he kind of, I don't know, just got swept into the whole marriage thing. And he was gone. So now when this thing happens, he became more involved with the family, more involved with my mom, he was, we used to go out there all the time. He doesn't really go out there much anymore. So he was kind of there, and now he's not. So now I feel like I can't really go to him for anything. But he's still a good guy, he's so kind, so compassionate, still around (?) for all the events but he...(garbled) but I know to call him up and ask him, 'How do you feel about Dad?' I may or may not get a response." "That could be. It could be a part of it. All of the spouses. Because the spouses are not, Jbrother's spouse always, I think she'd like to be a lot more involved with Dad's care but she has a tendency to take over... when she's there. So there's been a few mishaps in that situation where she upset my mom, you know, she's pushing things and that kind of...it worked out but that's a problem in that situation... It's hard. It's hard. (laughter) I'm sure he struggles with it. She's a strong force and my mom is a strong force obviously, so (garbled) there's been a number, a few things, hell blown away, and he did help her but now he's kind of pulled away. And (something garbled) his wife, she means well but... That could be a part of it. And the other siblings and their spouses really don't. They're concerned but they don't step in." "Well, I think they're just, they're taking care of their own lives, it's not about ten now, now it's about me! Or "I have a family here and I don't want to move from Oregon or Seattle, I don't want to leave. I don't want to uproot anybody."SHARON</p> <p>"Um, with my dad now it's not a whole lot because I'm taking care of my son" "I'm, right now I'm just sporadic ... Yeah, because, my job is nuts" "So, yeah Jsister, my sister, younger sister, she has two kids. She's busy... she lives in Fairview Park. Jsister lives in Macedonia. She's got two kids... Yeah. She's not an RN... an LPN? But now she's on the administrative side. So..." "If there's something I could do for her just to fix the house up and make her life easier, uh, then I would absolutely do it. But, then, then you turn around and you start getting closer to home and you're like, it takes an entire day and other things have to get done.. Yeah. I had to pull back in some ways, because it was just too emotionally draining.." KEVIN</p>
4 Burden versus Fairness (Mesosystem)	MATTHEW.5.4-5.6, 5.18-5.20 ZOEY.34.30-34.32;	<p>"Because my mom was aging and declining. It was because my mom's growing need for care. And in particular, as a sub-point to that, feeling that it was unfair to burden my sister with doing all of that by herself... 'cause I was, you know, 375 miles away in Chicago, and I didn't think it was fair..." MATTHEW</p>

<p>36.18-36.21; 43.3-43.8; 12.1-12.5</p> <p>JIM.21.1-21.11; 60.12-60.14; 68.3-68.14; 70.17-70.20; 71.1-71.8; 69.1-69.9</p> <p>BO.17.10-17.12; 55.11-55.22</p> <p>STEVIE.2.1-2.10; 37.1-37.9; 12.9-12.28; 13.19-13.20; 34.13-34.19; 35.9-35.13; 35.23-35.29</p> <p>MAC.46.2; 50.7-50.8</p> <p>ERIKA. 17.19-17.29; 19.9-19.12; 46.18-46.29</p> <p>PATRICK.5.10 - 5.13 ;12.4; 12.13; 31.2 -31.18;</p> <p>SHARON.20.8-20.20; 51.7; 53.15-53.17; 80.24-80.36</p> <p>KEVIN.14.17-14.25; 15.1-15.3; 29.22-29.25</p>	<p>“It has become – I can comfort her now. And I want to because she is a lost soul. And if there is anything I can do to make her less lost for this period of time, I will. But I thank god that I only have to do it once a week. I’ve made my peace with it” “You know at one point I said to him – because my mom was – we had worked so hard to work something out and she was like so critical, and I turned to him and I said, “why are we doing this. You know. What is wrong with this picture?” and he said, and I said at the same time, “dad.” “Because it’s really hard to turn yourself into knots to make sure that somebody is comfortable and then have them be insulting.” “And he, for those first few weeks, he took care of me 24 hours a day. And you know one of the problems in hospitals is that nurses can’t be available to you always. But I couldn’t more. I didn’t have use of either leg. And when I had to go to the bathroom, I had to go to the bathroom... Oh, I had to use a bedpan – right? ‘Cause I couldn’t get out of bed. And this guy wiped my butt. Do you know what I mean? And one time, I was having trouble getting one of the surgeons to listen to me – surgeons are of assholes. And he put together two wooden chairs and slept by my bed, because they came to rounds around 6am and he wanted to be there to advocate for me. Right.” “I: Yeah. That’s an interesting analogy because then you guys are so, seemingly, so close now. The connection, I mean, he moved to Cincinnati because he didn’t want you to be stuck, with all the care. Z: yeah.” ZOEY</p> <p>“So I was like, okay you don’t want him to drive at night, its Sunday night how could you, how could you solve this problem because you’re concerned about it. Just say dad, we’ll go out to eat with you when are you leaving and we will pick you up. That’s the concrete part of it... Right, so that’s in dealing with my brother who is very sweet, very well meaning, loving guy. Its just like, its just it doesn’t happen. So its frustrating to me” “Umm, yeah, the caregiving thing works really well and Bo and I have often talked about... we are befuddled that RBrother doesn’t do more, spend more time with Father but you know on the other hand Father may have to do with that also.” “RBrother obviously does it in his way by saying, ‘dad shouldn’t be driving... And you know and the hardest part the hardest part is not embarrassing RBrother.. Like he’s not like that he doesn’t have the capacity.” “Well no the biggest burden is trying to keep Father under control... Cause you know he, if you say something... the it’s the biggest burden is to get him to behave himself” “Its like with the junk mail umm... he’ll say, ‘well I don’t do that’ and I’ll say, ‘well I have access to the checking account online’ or you know I won’t say it there but sometimes he’ll write a letter this thing to people and we looked it up on Sharing Navigator so its that kind of stuff” “Its like, ‘I wish you could do this’... Yeah because you know cause we all love our father and we are interested in his well being, its like I really wish you could like when you see something you could take action and take care of business” JIM</p> <p>“Well yeah and RBrother has a retail store and Jim, you know he’s involved, he would have to really plan out time off to do that so that stuff sort of fell to me but I enjoyed doing it. It wasn’t a burden at all.”</p>
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		<p>“Yeah it was sort of delegated to [Jim] but as yeah it’s his baby ... He’s the eldest child and some how my parents... I mean its really weird because they set up this thing in Florida in the wills and the trust whatever it is... Yeah and trusts or whatever and I’m just like umm... I remember at one point it was like because my parents have always tried to do things very evenly but then all of a sudden it was like there was after my mom passed away she had a trust but it was Jim and RBrother and I wasn’t on it. I was like well whatever” BO</p> <p>““that 50% of the time or at least 6 months out of the year she is Manila based in the Philippines and then the 6 months that she comes to the States we divide her time between my sister in LA and me over here in Ohio and occasionally she flies over to my brother in Vancouver. But that is kind of between my sister and I and Mac in Ohio and LA. It’s like a 50-50 as well... With my brother, right now it is my brother. It used to be my sister for years but now it is my brother. So we’re kind of like just doing the rounds between the 7 siblings” “Yeah I was a little frustrated about that because I set up the call and three out of seven maybe so I wasn’t really upset but I just told the group ‘is this really necessary?’ If not everybody can make the time to get on it either we change the schedule or we scrap it all together. So right away they said ‘no let’s not scrap it we will make an effort next time.’ So it is just a matter of just setting things into place and I don’t want to be boss about it so I am just being tongue and cheek about the whole thing. I am older than some of them and I just feel like you know like lets just not make this a new issue. The issue is mom not just getting on the call. We just have to try harder.” “There is not a day that goes by to my sister, to my brother, to my auntie, to my relative that she says ‘did you know we broke up?’ That’s how she starts, ‘did you know we broke up?.. It’s sad too’ “And they were like ‘should we do that?’ We are trying all these things: ignore, get mad at her, tell her to change the topic we don’t want to hear it” “there is that financial thing it is a real thing. That’s where I hope we are still on the same page. It can cost anxiety like you know my sister would say ‘oh my gosh we spent this much and before she left I gave her a lump sum.’ So but see before you okay bottom line you want to anticipate that anxiety by getting organized instead of a sibling kind of feeling ‘okay I wish you’d be more sensitive to that because I am hosting her now, I am paying for her.’ So we definitely have to talk about that” “Yeah usually well she stayed with my sister for a long long time so my brother said ‘hey its my turn... But sometimes it could be who knows it could be a burden to my sister-in-law and she’s not saying anything” “Yeah she’s married and she just kind of umm my brother just said ‘maybe it is my turn.’ It was stressing her out and my brother-in-law there was a little bit of stress there yeah with my brother-in-law but it wasn’t like... we were able to fix it and then my brother said, ‘maybe it’s my turn to take care of her.’ It is also a big burden to take in even if it is in our culture to take in your elderly. Here in the States you put them in homes but back home we take them in and its not always easy so” STEVIE</p> <p>““In a way I sense it that my mother might be getting in the way of his lifestyle now.” “Umm when she was here last she would it wasn’t that big of a problem. She was doing dishes and helping out with the</p>
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		<p>laundry” MAC</p> <p>“Um so um when my mom came here I remember KBrother saying something to me like well. He implied it was just a given. Well of course she would.. So I thought oh that’s interesting. And literally what happened when I brought my mother here is I know that the three of them breathed a collective sigh. Like phew!.. Yeah. Like well we don’t have to worry about her because she’s at Erika’s. And Erika will take care of her” “I don’t know. I think it’s the daughter will do everything. And their sons ... I think it’s the mentality. And that because I’m the daughter it is my responsibility and that I probably enjoy doing it. And it was just a given, I’m sure in their minds” “I dreaded the whole process. I dreaded it because I knew my mom would not be happy with it. That was the hardest part...My initial feeling after this meeting with the girls was, I can’t do this. But when I came home that night, I wrote and email to my three brothers. And I said today my three daughters lovingly told me that grandma cannot live here anymore. And I said they know better than I do. And they can see the reasons. And so I want the three of you to figure it out. And just let me know what you come up with.” ERIKA</p> <p>"Yeah Erika did. You could tell she was upset and it was the pressure getting to her.” “The first time Gbrother took her over on a weekend the first time he took her my mom cried the whole time.And he took her back to my sister and my sister told me... Erika goes this is becoming very burdensome for us and if things don’t change, something like you know I’ll drop her off at your house for three months and you will have her" " "It is a lot more especially for Erika. I can’t imagine having her, as much you know we love our mother but it gets very aggravating. It’s the hearing problem you know umm... when they get older they are like little children and my sister used to try and get my mom to walk more and do exercises. Well then she’s the bad person, it’s like just not happy and the disciplinarian like and then Erika would get the brunt of everything. Trying to make her walk and trying to explain to her the blood..You stop walking and you are going to get worse and worse and worse.” "It is a lot more especially for Erika. I can’t imagine having her, as much you know we love our mother but it gets very aggravating. It’s the hearing problem you know umm... when they get older they are like little children and my sister used to try and get my mom to walk more and do exercises. Well then she’s the bad person, it’s like just not happy and the disciplinarian like and then Erika would get the brunt of everything.” PATRICK</p> <p>“It would just be, well, the problem is that a lot of good buying jobs are out of state... Yeah, I know but I just don’t see myself doing that because I have this connection... I really feel like I can’t leave because of this... It’s hard. Really strong pull. Close with most of my siblings really. And to pick up and leave, I should have done that when I was in my 20s and got it out of my system and moved back here when I was 54” “Now she can focus on what she needs in her life. Kind of look beyond what’s been going on.” “Even though this is a big deal to me and I see it as paramount, I...I was unemployed three years ago, and I could have taken this job out-of-state and I didn’t, because this thing was looming.” “I mean the point that</p>
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		<p>he was moving to the home was perfect in time because she was kind of done with it but she's, I think she's past that, I think she's past the drama of that marriage and now she just sees him as a human being that needs help." SHARON</p> <p>"Yeah, It's stressful. It takes time. SO, there's the travel element and then there's the energy level. If you're going to talk to your parents and one's in a nursing home and the other one is trying to piece it all together. You have to have a certain level of energy to be able to handle it... Because the last thing you want when you go out there, is to go out there and be overwhelmed with the enormity of the situation. And, you come away leaving there depressed and sad and, mom is not really feel good about it and dad doesn't know one way or the other. Um..." "You come away drained. You're drained" "[Sharon] gets wiped out too... And then she feels like why isn't anybody else stepping up like her. Cause her perspective is different than ours." KEVIN</p>
5 Sibling Closeness/Unique Bond & Alliance (Mesosystem)	<p>MATTHEW.19.6-19.9; 25.3-25.6</p> <p>ZOEY.8.21-8.25</p> <p>JIM.11.20-11.21; 12.9-12.22; 16.13-16.18; 46.2-46.5; 75.6-75.20; 76.6-76.7; 78.5-78.10; 39.8-39.10</p> <p>BO.34.7-34.8; 35.25; 36.1; 55.6-55.9; 36.4-36.7</p> <p>STEVIE.19.4-19.14</p> <p>MAC.26.18-26.19; 27.3-27.10; 27.24-27.26; 54.5-54.14; 55.22; 57.2-57.14; 58.6-58.15</p> <p>ERIKA.19.14-19.15; 26.9 - 26.16; 18.31 - 18.35; 19.1 -</p>	<p>"We can hash things through. I listen to what she has to say and give it great weight. And she listens to what I have to say and gives it great weight, and we can come to a meeting of the minds to decide what the best thing to do is." "And again, that's form of support between us. Like the kind of conversation that you might otherwise have with a spouse, but neither of us is married right now. So happily, we each have somebody close enough to us to have that conversation with, you know, and be listened to." MATTHEW</p> <p>"He ran interference for me from the time I was tiny. And I felt I could always trust him, and that he would always be there for me... Um, yeah. We were very close." ZOEY</p> <p>"Yeah, so anyway, [Bo] he's he has a very artistic uhh sort of temperament. ..And and we have a very similar, my brother Bo and I have a very similar worldview and perceptual aesthetic" "[Bo and I] talk probably I would say two or three times a week" "My brother RBrother is very concrete." "So that that's a difference in the communication, a difference in the emotional connectedness and the kind of richness of the relationship." "But my brother, RBrother, no it was RBrother actually my brother RBrother who I, I do love him. We do love each other we get along. I: Even though you have different approach to the world. J: Yeah right." "Bo uh, we were looking for schools for him and we went to a place called uh... it was basically a progressive school up in Williston, Vermont and he said I am forever grateful for you basically influencing mom and dad for letting me go there," "actually with Bo yes I've done that. When he's in Rhode Island I'll do that or... Or he'll come here sometimes just to hang out for a little bit... We enjoy each other... So yeah we have a lot of social non-Father time in Springfield... well Bo has made an effort when I am down in Springfield to be in town unless he has got work in Rhode Island or something is going on in Richmond" "with RBrother its not that much I mean he's come, he came up for my 60th birthday five years ago 6 years ago" "Its just sort of that kind of stuff, checking in [with Rbrother]" "I: Yeah, does umm does RBrother play an instrument or anything like that? No, he messes around with the</p>

	<p>19.6; 20.1 -20.2; 20.8 -20.10; 20.12 - 20.15; 21.21 - 21.32; 26.22; 26.28; 27.26 - 27.31; 28.2 - 28.3;</p> <p>PATRICK. 21.1 - 21.5; 2.12 - 2.19; 4.24 -4.31; 10.15 - 10.18; 10.30; 11.1 - 11.12; 27.5; 27.12 - 27.13; 49.26 -49.29</p> <p>SHARON.22.15- 22.17; 23.3; 23.21; 25.4-25.5; 25.21- 25.22; 27.4-27.11; 27.19-27.22; 28.4- 28.10; 31.3-31.4; 32.15-32.25; 33.13- 33.18; 48.22-48.23; 52.12-52.20</p> <p>KEVIN.14.2-14.6; 18.10-18.11; 30.5- 30.8; 30.14-30.15; 31.13-31.15</p>	<p>computer and I I I he's a mystery... Yeah, he's a man a mystery to both Bo and myself." "it just I think it just turns out that [Bo and I] feel much more connected in terms of our perception of the world or interests and that kind of stuff" JIM</p> <p>"yeah I mean we just enjoy each other's company. We enjoy what's out there and we see what we are amused at and we just work off of each other basically" "Yeah we're very close and our thought processes are... we're basically on the same wavelength in terms of our worldview I think." "So Jim and I talk regularly pretty much and he appreciates to at least to have me to bounce ideas off or at least to vent but I mean we can talk, we have the same concerns and he's sort of more in it because he's viewing the financial, he's got his hands in the financial stuff" "you know I love him dearly .. Right and he's probably one of the sweetest and humble people I have ever come across" BO</p> <p>"And I know that it has been common feedback from our bigger clan, relatives how they would always say 'you guys are so close... Friends would always say 'you're like one big group of friends' because you know similar ages. We can all go out together, party together so where as some families with siblings don't really do that. We were really close each one got married; we were always so sentimental about that. So the dynamics in our core family, the seven siblings was really very close like my maiden names is Tomas just like Mac's is so we used to call we still call ourselves the Tom-Team" STEVIE</p> <p>"I: who do you connect with who are the players in your family life that you connect with regularly?.. Okay, it would be my sister Stevie because she is here." "If it was before when she lived in Avon every weekend... But now that she's off there its like whenever. They would come here get together and I would go there. How often? It's been maybe once a month at least... I: What about talking on the phone or Skype... M: Sometimes it would be a week, once a week, sometimes every other day" "Yeah so I would interact with Stevie who I see, closer to my older brother although him being in Canada and he has his own dynamics with these problems and blessings. So sometimes we don't get to chat. "I was going to say we were a very close family almost like an ideal family in the Philippines. Some called us compared us to the Sound of Music family... Very talented we always come up with shows at Christmas. So in many ways we were very close. In many ways we also different in thinking, in agreeing whether we agreed on something or not so I would generally call it, we are still very close at this point. We still care what happens to one another.. We contribute to each other like if my eldest brother needed some help cause he's had kids he's had some problems with his kids" "Umm [Vbrother and I are] like... part of the same coin. He's one side and I'm one side" "[Gbrother and I are] not; I'm not as close to him as Vbrother. Vbrother is a lot closer to him." "My relationship with Msister we were in LA and I lived with them for a while... And we were in many ways close I mean she was very happy I was there. I got along with her kids" "then Rsister well Rsister I said married my classmate in college.... Every year and then Lsister when I was home we used to be closer. Now its like, I still text her on her birthday and all that but</p>
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		<p>we hardly talk.” MAC</p> <p>“Yeah. It was very interesting. So I probably ... you know as close as you could be to siblings you know we all had really good relationships but when it came to the care of my mom, it got interesting”</p> <p>"KBrother just had the wrong perception of this. The wrong perception. Which started way back. And I think the straw that broke the camel's back is when Patrick had to play the reasonable one in the family even over his oldest, oldest brother. And say, you have to do more here and it was not. I mean I don't think either of them took it well but KBrother took it really bad. I mean at least GBrother modified his behavior." "And then Patrick started to realize how much work it was. Much quicker than the other two ever caught on. And Patrick always said to me, you guys are saints. You are saints. And he would just say thank you for doing this." ", KBrother said to me once when he was bringing my mother home. He goes, after my mom came in and sat down he goes I got this email from Patrick. He said I couldn't believe the stuff he said to me. And I knew what was exactly what he was saying. Yeah what was in this email? He says he told me that I couldn't take mom, that I should take her to a hotel. He says, can you believe that. And I said Patrick, I said to KBrother, Patrick's only motivation for this email was to help me. He just wants a little bit off of our plate. That's his only motivation. Just to get more help for us." "I think the support he gave me throughout you know those three years. It meant a lot. You know. And that's just something he didn't have to do. But you know he did and I think that brought us closer together." ERIKA</p> <p>"No sailboat, smaller sailboat it's called a Highlander about 19 feet 900 pounds. But I used to crew with [GBrother]. So we got bonded a little more during that time. We traveled a little bit, did some regattas, and I raced with him down at Edge Water on the weekends, Wednesday night's, and Sunday mornings. So we got we became closer probably during that period." "so when we had these periods... you know my sister would call her and she's not sounding right can you go over there and then the one time you know we called emergency to come over and she went to the hospital and it just declined from there." "finally I sent an email to him saying, you're not helping out Erika by... you know you need to take her for the entire day and not just for four hours because it's convenient for you and then he took that he... he didn't know my sister and I talked about everything so my sister had a copy of this email because I sent it to her trying to help her out. When Kbrother went to Erika and said, oh my god you should see this nasty email Patrick sent me oh my god he's out there and I can't believe he sent this to me and my sister's thinking I saw the email and there was nothing mean about it. It was factual" "I remember the one time Erika was going out of town... probably the year before she went in the nursing home. Erika said she's going out of town. She told me before she sent the email out 'I don't want you to respond I want Gbrother or Kbrother to respond about taking her.'" "And I'm like no I'm like I've got plans I'm not going to be in town, which I didn't but" "The last time he (Kbrother) ever called me was to negotiate so he didn't have mom. So what he did, which was so bizarre. Erika had set it up for him to stay over there</p>
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		<p>at the house and umm... he came over but he didn't...what did he do? No he picked her up and took her to his house during the day, drove back there at night, and did what he had to do. He slept on the couch in the living room. My sister thought it was so bizarre." "I was talking to Erika and boy she was remarkably okay when I left. Well then we find out ..." "Well my wife you know and Erika. Erika took on more of the leadership role and making sure everything is taken care of and you know so me and Erika communicate with each other because she knew we were doing what we could. Trying to get the other siblings help so she appreciated that." PATRICK</p> <p>"I: So who are the people you connect with like on a weekly or daily basis... Hmm, sisters mostly. Esister and Lsister. Jsister. Asister's my closest I think. We have the same voice. It's weird" "Yes. She's my closest but she's in Canada" "Yeah, we do and she's, she's, I see her every couple of years or so..." "Lsister, once a week or so. Esister, every couple of weeks. Jsister, like once a month. We talk about , you know, a lot of things. Like Jsister I can't really talk about this with" "Yeah, we do. [Jsister] has two girls and we talk about that. So, yes, there are definitely a myriad of other subjects. It's just this one, I know, it's, it's just hands off" "I: But umm, so umm, so how often do you and Esister connect? Or do you guys connect in other things besides this kind of thing? ... S: Yeah, we, next week we have dinner plans... then there's a martini fest at the house... Yeah, we're tight. We're tight. Yeah, she's, we've helped each other thru some tough stuff through the years so, yeah, definitely we're" "Well, my brother Cbrother in Oregon, we're close, pretty close, umm, Mbrother, not so much. I see him at family outings. That's about it. Jbrother, he's the next one closest to me, a year younger than me. We were tight for a long time and then he got married and things changed, and now, not so much" "We, all of them, Cbrother we could be on the phone for an hour and talk about everything, his two girls, his ex-wife and his girlfriend and my dad and he's got some real good insight into dad's situation... He's pretty, I think he struggles with things being so far away... So he's, but he's willing to talk thru just about anything that's going on" "Good overall view. And that took time to do that, it didn't just...it was very gradual and we weren't really sure how this would all work out..." "Um, compassionate, empathetic, trustworthy, can tell her pretty much anything. [Asister] really smart about seeing thru the chatter, you know? Definitely. And firm. That's when I have to be told to shut up... Well, it's nice that someone calls me on my crap sometimes" "[Lsister's] my a..., she's a tough blonde, I mean she's beautiful person. A beautiful woman. (something garbled) but she doesn't really know, you know, she's beautiful inside and out. She's just, I don't know, the same thing, compassionate, empathetic, tough-minded, she's trustworthy, she's loyal, can call her anytime, day or night, text her anytime.... She'll really listen" "So then when we all grew up and got our lives we decided we were going to change that so now we're a very huggy family...." "I don't think we have changed much. I think my, my perception of our various relationships has changed. Because I thought that we would always be close, tight, like be us against the world and that's not how it is and we are... Yeah...like it was us against the world like we would always think alike and be alike and fight the battle and it's not, we were...we kind of fragmented.." SHARON</p>
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		<p>“I mean it’s good that we have lots of brothers and sisters, but it’s good and bad because we each try to do whatever we can but we never know what the other person is doing so all of us know a little bit, but none of us know everything. And, time is short during the day it’s hard to communicate with everybody because there’s just so many of us.” “I: How often do you go see them? ...K: I’ve only gone out there once.” “I: yeah. So, tell me, what, who’s your closest relationship with ... K: Sharon and Lsister “ “With Jsister, I wish I could be more involved in her life. Uh, but it’s just logistically it’s hard to keep up. I get along with her fine” “Um, with a, with Dbrother, he’s on the west coast. I was closest with him until we got done with high school, and then he made his own life. And, he just pretty much cut ties and left”</p> <p>KEVIN</p>
6 Initiative Taking and Decision Making – Stepping Up (Mesosystem)	<p>MATTHEW.19.3-19.11, 19.17-19.18, 32.9-32.10</p> <p>ZOEY.1.32; 2.2-2.4; 30.18-30.20, 30.27-30.28</p> <p>JIM.21.1-21.4; 28.14, 28.16-28.19; 32.4; 55.23-55.24; 56.1; 10.7-10.8; 32.1-32.4</p> <p>BO.1.14-1.15; 2.5-2.9; 16.24-16.25; 64.8-64.24; 52.14-52.16; 52.24-52.27; 53.1-53.2; 63.11-63.21; 67.6-67.10</p> <p>STEVIE.2.15-2.17; 30.12-30.17; 33.14-33.17</p> <p>MAC.44.26-44.27; 44.29-44.30; 45.8-45.10</p>	<p>“We could share that responsibility and we would not end up at loggerheads ever. And we would be able to work through, sort out, come to agreement or compromise on whatever was required in order to function well as co-executors. So we are, and I believe that is in fact the case. We can hash things through. I listen to what she has to say and give it great weight. And she listens to what I have to say and gives it great weight, and we can come to a meeting of the minds to decide what the best thing to do is. We don’t necessarily always agree. It’s not that we don’t have disagreements, but we have enough of a relationship, you know a dependable relationship that we are confident in being able to hash it through and work things out.” MATTHEW</p> <p>“Um, I would say [snickering} that I worry about my mom. That’s a big ... Um... eight hours a day. Um, I spend time trying to think of things [Fraggle the dog whimpers] that will engage her attention when I go to visit. It’s like making a lesson plan.” “It’s exactly correct because I am very organized, and so to make sure that all of her bills are paid, I can do all of that. I fundamentally have no understanding of the big picture. He is a big picture guy. And so it’s perfect. I understand what I’ve got to do, and I do it. The big picture, I don’t know what I would do without him because I don’t get it.” ZOEY</p> <p>“So I was like, okay [Rbrother] you don’t want him to drive at night, its Sunday night how could you, how could you solve this problem because you’re concerned about it. Just say dad, we’ll go out to eat with you when are you leaving and we will pick you up. That’s the concrete part of it” “I’m in charge of his finances” “My role besides emotional support and just you know talking to him pretty often during the week is uhh making sure the finances, all the taxes, basically any any and some medication stuff but just the financial stuff making sure that his investments and his social security.” “two or three years ago I basically took over” “Well anytime I’m in Springfield and we have things to talk about I try to get Bo and RBrother together. Sometimes its harder for RBrother to get over there, its like I ... don’t get it but...” “Umm, and [Rbrother], so that’s uhh I have contact with him not, mostly I call him more than he calls me.” “Yeah it was like, it was creating a corral for the medical tax financial stuff and slowly but surely</p>

	<p>ERIKA.16.14-16.26; 46.26-46.31; 47.3-47.15</p> <p>PATRICK.2.12-2.13; 3.6-3.29; 3.20 - 3.28; 5.18; 7.4 - 7.12; 34.12; 34.30; 36.11 -36.12; 36.24 -36.25</p> <p>SHARON.4.17-4.18; 5.5-5.6; 12.3-12.4; 26.2-26.3</p> <p>KEVIN.29.9-29.18</p>	<p>we lassoed it all up.. And put it in and then two or three years ago I basically took over yeah” JIM</p> <p>“Yeah sometimes more than once a week and if I miss him or feelsing funny I’ll just jump in my car and go over there” “Yeah that’s right. Yeah no I did, he’s close geographically and I feel it is important that I spend time with him especially at this point in his life and that’s also one of the reasons I sort of came back here because you know he’s not going to be around forever. I’m an hour away, its not that big of a deal my father’s here, my wife’s parents are still living, he’s still living so I think it is a good mix”</p> <p>“Umm... and I would fly down there and drive him back. We would drive back together or I would drive down there with him and fly back and spend a few days with him. But I had the luxury because of my video production I had flexibility in my schedule.: “So we have tried to set that up with him with varying success... I just take care of it and so does Jim because it is just what needs to be done and its over.... But with this there is the whole family watching and I don’t want to let Jim or my father down. I mean it is important to do it is just one of those things that is important” “Yeah, last weekend I had set up a conference call because Jim had called and I said look lets get RBrother in on this because something had come up and I just did a conference with the three of us.” “Oh no its just something that we’re supposed to... so like Jim will call him maybe on Monday, I’ll call on Tuesday, RBrother will call on Wednesday this was the schedule we made up Jim on Thursday, I’m supposed to call on Fridays, RBrother calls on Saturdays, and Sundays we’re supposed to take him out to dinner “ “Yeah I’ve initiated some conference calls from time to time umm... just because that is the way business is conducted generally in the really world” “So I told Jim I would just print the envelops up so when I came back from Rhode Island last time I’ll have a stack of envelops for a couple of years for each of these addresses ... Well yeah that’s the idea. I don’t know what I mean that is sort of my understanding of what we’re supposed to be doing as a family...In supporting each other and that’s why Jim was so bonkers when he got no response from RBrother. Its like what the hell do I have to come down there and do it myself and then on top of that I don’t want to be the asshole here which is like you know” “Right so... Jim and I thought it was pretty clear that RBrother would see to it that.. Right, well it became apparent to me that that wasn’t happening so now I have just taken it upon myself to just do it because if RBrother’s not doing it than what the hell” BO</p> <p>“Starting two weeks ago only three of us got on the call because the others missed the time. We see the need for it that we are all on the same page so we are really trying to streamline our communication.” “I volunteered, this is one of the ideas that came out of the Skype. I said ‘maybe we should have streamline communication. Let’s use caring bridge.’ And then also we had an idea of, we are seven siblings so we said one sibling out of the week, seven days a week, we said what if we are in charge of connecting with mom whether it is face time whether it is taking a walk around the block for those that are with her physically but we are each in charge of a day to connect with her” “we used to all have a contributing like we each equally contributed a certain amount of money to help mom. Whether is it shopping money or</p>
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		<p>just things you know we all thought it was responsible to give her an allowance from all the seven siblings.” STEVIE</p> <p>“Stevie was the instigator you know she took her Master’s in organizational development so she’s applying it. So basically it started with you know the venting through the text or through Skype” “. So from that time up to today we’ve been planning now if it gets worse we are thinking about what to do next” “So Stevie also suggested ‘look I have a website where we can all blog in a keep a record of what is going on.” “MAC</p> <p>“And um so you know the one day when I went there and she was like totally didn’t know where she was. Like there’s no way she way can stay here... And um so that was the day I packed her a bag... So I brought her here” “My initial feeling after this meeting with the girls was, I can’t do this. But when I came home that night, I wrote and email to my three brothers. And I said today my three daughters lovingly told me that grandma cannot live here anymore. And I said they know better than I do. And they can see the reasons. And so I want the three of you to figure it out. And just let me know what you come up with... I was like empowered then. And I’m like okay – I’ve done this for three years now. You guys are gonna do this. I’m not running around” “And I’ll tell you they.. They rose to the occasion... Separately. But they did it... So and KBrother was actually the one that found Elmcroft... So he looked at that place. He looked at a couple of others. GBrother looked at a few. Patrick .. They all did their homework. And they reported back to me and they would say I think this place warrants a visit from you know somebody else. And I did look at a couple” ERIKA</p> <p>“Yeah and so I was the closest one so when we had these periods... you know my sister would call her and she’s not sounding right can you go over there” “My sister stepped up to the plate more than anybody... Yeah, it’s always so that’s how it kind of... things started and my sister finally... it came to the point where my sister said you know she can’t stay here I need to take her in... I: How was it decided that she would be the one to take her in?... P: She stepped up to the plate... Yeah she goes she (mom) can’t stay here by herself... god bless her for doing that you know. She did it in, it obviously talking to her I was never in that role where she lived with us ever. I mean since years and years obviously so Erika took that on and got to see day to day what that was like” "Yeah, it’s a ways so that’s how it kind of... things started and my sister finally... it came to the point where my sister said you know she can’t stay here I need to take her in. She stepped up to the plate. Yeah she goes she (mom) can’t stay here by herself... god bless her for doing that you know. She did it in..." "Now we stepped up to the plate more than my oldest brother and Kbrother." "And I think the first weekend we took her was... it coincided with a baby shower for Erika’s daughter-H I think... I think that was the first weekend it just... Yeah it’s just like let’s just take her and get her out of your hair for the weekend. It was one of the first weekends... So we stepped up you know" PATRICK</p>
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		<p>“so in between there and Avon Oaks was a myriad of other facilities that she looked at, we looked at together. And my brother would go and we’d take turns” “Yeah okay and you’ve got to(present?) yourself to that fact first and then you just try to pick the one closest to where my mom lives “ “My mom decided, “Okay, this is it. We’ve got to watch out for him, got to take care of him.” “Yeah. [Jsister] does. And if something were to go wrong, she would be there. She would come home and she would help. She would do all that.” SHARON</p> <p>“And, that’s where I’m counting on my older brothers and sisters to step up because they don’t have a teenager. They’re not a single parent. They’re not on the other side of town. They ones who live closer... You know, you think there’s a pecking order to the responsibility to take care of the parents. The older ones who have, maybe not the resources, but the time... More flexibility, you would think those would be the ones to step up... We’re lucky that there’s enough of us, um, it would be much more difficult if there was fewer brothers and sisters because then everybody would have to step up more” KEVIN</p>
7 Use of Professional Role/Education in Caregiving Approach (Exosystem)	<p>MATTHEW.33.26-33.29, 34.1-34.15</p> <p>ZOEY.26.13-26.18; 32.13-32.15; 39.10-39.13; 43.18-43.23</p> <p>JIM.4.14; 5.1; 65.12-65.13</p> <p>BO.64.14-64.24; 29.7-29.9</p> <p>STEVIE.27.21-27.28; 43.23-43.28; 29.15-29.124</p> <p>MAC.4.4-4.7; 42.18-42.19; 44.25-44.27; 45.8-45.10</p> <p>ERIKA.3.10 - 3.11; 9.3; 13.6 - 13.29; 43.14 - 43.23; 45.4 -</p>	<p>““Um, my degree’s in psychology [laughing] as so it happens. Yeah, I did my master’s work ...in Psychology. Community psychology, And I actually had to do some clinical work, ... I went on to be a, I guess you’d call it a healthcare researcher. My emphasis in graduate school was on program evaluation, social program evaluation. And I did most of my professional work in healthcare quality improvement. Measuring health outcomes and improving health outcomes and that sort of stuff. I started out doing that in a psychiatric setting... And that’s what got me started on quality improvement”</p> <p>MATTHEW</p> <p>“So I. I don’t give up... I brought all my clinical skills to the table. And I sat down with her and I said, “Mom, I know this doesn’t make sense to you but this is what is happening. And you need to understand that Matthew and I would never make a decision for you that was not in your best interest.” I mean, I just put it all out there!” “She would have very close friendships for a period of time and then something would happen. There’s discarded bodies along the way. Right, this is clinical training in action because you are either a good object of a bad object “ “I am. And you know, people describe their families. A good relationship is “I talk every week, once.” And most people – early on in my career when people would say, “oh I have a close relationship with my brother.” I would say, “Tell me a little about it.” [and then they would say] “Yeah we talk about 3 times a year.” And I would say...” “I think that I have translated a world, that many times mystified him... The world of feelings. I have really helped him, over the years, in some dimension of interpersonal relations because he didn’t get the affective part. They were mysterious to him. And he does listen to me. And I think that – we’ll see what he says – but I think that he feels loved, and supported, and not alone.”.ZOEY</p>

	<p>45.5; 56.38; 57.2 - 57.7; 59.7 -59.8; 66.29 -66.33; 67.4 - 67.15; 73.22 -73.34</p> <p>PATRICK.33.2-33.7</p> <p>SHARON.26.7-26.10; 33.18-33.21; 34.8-34.9; 87.5-87.9</p> <p>KEVIN.20.21-20.24; 24.21</p>	<p>“Yeah I function as a, I’m a geriatric psychologist” “I see clients with dementia everyday” “Well see as a psychologist its easier because I am always, professionally I am always concerned about people’s well-being.” JIM</p> <p>“I just take care of it and so does Jim because it is just what needs to be done and its over...And that’s just I guess he was trained in his professional life and I have to think that was how I was trained in my professional life though there is a lot of stuff that seems to not get done... But with this there is the whole family watching and I don’t want to let Jim or my father down. I mean it is important to do it is just one of those things that is important.” “Yeah we did that and you know I had my laptop what the hell I came from the corporate world. What the hell? Jim’s very organized so I just took it to my level and then we shared it among all four of us. I mean dad got copies.” BO</p> <p>“And yeah but he’s the type of guy, you see it as young children, he would set goals, he would have illustration boards, visualize. He will use all these techniques and strategies like you know how to have her walk with the kids, watch their activity. So he has all these, he is a very creative person. He has all these great ideas about goals or visualizing or steps to getting to your goal but maybe that’s why it frustrates him. He is trying to handle my mom in this very .. Structured and boards and visuals you know” “So if I don’t watch it now, if I don’t pull all those techniques, and dig into my inner strength and values I mentioned I have because of my dad how do I carry that with me as her disorder or condition gets worse. How do we maintain or sustain the strengths and the healing strategies for us to help her without losing it without becoming insane ourselves or being stressful ourselves?” “This time we just said it cannot happen so my sister is going to take her to LA. LA is a one; there is no stop over, I think it is a straight flight and my sister works in the airlines so sometimes we can... Lsister, she works for Japan airlines. Usually you can have people wheel chaired ... Door-to-door until the one who receives her gets her ... Yes but we’re still thinking she already needs a companion” STEVIE</p> <p>“So we text each other. So it is a little stressing for them. So I told them, me having the experience with my father-in-law. I told them she’s going to go fast if she doesn’t get treatment.” “Right so and I know from the stories and my dad-in-law would come visit when we were living here and he had dementia you know” “Stevie was the instigator you know she took her Master’s in organizational development so she’s applying it. So basically it started with you know the venting through the text or through Skype“ “”So Stevie also suggested ‘look I have a website where we can all blog in a keep a record of what is going on.” MAC</p> <p>"And the more I read about it since having my mom here. It’s something that should be dealt with early on when a person is aging so that they get used to the hearing aid and they .. It’s part of their every day life." "And you know it is the sibling who is in town with the parent who takes the brunt of the care." "she</p>
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		<p>displayed Sundowners Syndrome. Which I didn't know anything about that. But in fact from what I read Sundowners Syndrome is a behavior that shows itself before dementia or part of dementia development." "And I didn't even know what kind of facilities were available for her at this stage because I don't know. Unless you do your homework way ahead of time, this situation falls in your lap and then you figure it out as you go" "There's a book called the 36 Hour Day. Have you heard of that? Um and it's the story of care givers and what they go through and um .. and you know the progression.. they forget to chew when they eat. I mean all function goes away. So I know.. Intellectually I know what's down the road." "And you know I, I tried to find outside help. Like the Alzheimer's support group. The facilities the county has but there have to be people who are doing what I was doing who have no clue that there is any support out there. So how do you get that information to people who need it?" "Um, I guess it's kind of what I talked about most recently. And that is that I think people who find themselves in this situation with a parent, you know, don't know what help is available. And you know how to go about coping. You know and getting some relief. So, I don't know. It's just there's not bulletin boards out there that say hey, call this number if you've got a parent that's losing it. You know. Yeah. You know. Um, because not everybody, you know is curious enough to try to find it on their own because they don't know it exists. So I don't know how we help like the general population. And part of me thinks that maybe lower income people might have .. I don't know, they might have more opportunities. I don't know. I know that my mom didn't qualify, you know, for things .." ERIKA</p> <p>"There are some people who are physically capable. We would get it when I was a cop in Royalton. We would get people walking around who had escaped from their in-laws house. The parents are at work and they leave them at home during the day" PATRICK</p> <p>"And Lsister, she's a nurse, a trained nurse. So she's very, well she was pretty involved with his medication issue... So she would go thru his meds and stuff so she's involved" "[Lsister] also helps me with Dad because she takes all the facts, "Okay, what did he say to you? What is he taking?" She drills it down. "This is why that's happening. This is what I think Mom needs to do." And then she'll, she'll kind of like adds a calming perspective to what the sadness is" "She knows her drugs and affects of drugs and what I can find out about that, "I know someone I can ask about that for you." So she knows the ins and outs of (something garbled). So..." "Kevin does the financials [for mom and dad] ... Accountant/financial at Nestle" SHARON</p> <p>"he's helping her with the finances too. He and I have put our heads together, and, of the bunch of us he is, he's had a corporate, he's a computer programmer, he's had a corporate job. He's more successful than most anybody else. So, he has the resources and the time and the organizational skills to help my mom." "Now [Lsister] has nursing knowledge, so she contributes that way." KEVIN</p>
Individual Care Recipient (Parent with Dementia) (Internal)		

8 Parent's Lack of Niche/Identity in Family System (Individual)	MATTHEW.10.1-10.16; 11.9-11.11, 14.5-14.7; 23.11-23.12	<p>"You are not going to take my car keys away!" So it was the opposite of what the experience of turning sixteen is. Once you get your driver's license, then suddenly you've got wheels, you've got freedom, you can go where you want to go. But here's my mom, at 80 years old, and suddenly she LOST that freedom. And she wasn't happy about it. And she didn't have any self-perception to realize that she was a menace to society." "You know, she was a very accomplished, professional person, and you know, to see her get to the point where she was barely able to do basic tasks, that you and I would take for granted in a second" "And it's weird, and it's my mom. And as I have said, who was once a very competent, and independent, and functional person, and in her dotage, she is not!" "I mean that.. whoo! Now we're getting to the department where, I mean, is this a life worth living? That this person has lost their identity." MATTHEW</p> <p>"Um, she still hates it by the way... She does not know what she is doing there" "She has lost – this was a very articulate woman – she has lost at least 50% of her vocabulary so it's like... Not any longer... and um, she shuffles, she's become very frail and she's teetering toward the last stage... And when I visit her she says, "Where's your husband?" meaning my brother. Yeah, it's confusing. Can you imagine living in a world where nothing makes sense to you?" ZOEY</p> <p>"Yeah, my dad is a 95 year old, 95 ½ year old only child... Only child, uhh... and had a great relationship with my mom... For close to 62 years and she pretty much was the engine that drove the train." "She died down there in Florida..." "Umm, and then he, it was, there were a number of traumas at that time in addition to her death." "But I think that the friends and folks he sort of connected with down there just had not they just sort of drifted away. I don't know how much of that was his behavior." "Its novelty and it is new stuff that is so difficult to deal with. So I told him, I don't want him on the highway and I don't want him to drive at night. I said, dad, I say this to him every time, if there is an accident you will be to blame because you are 95. It's as simple as that " "He's okay with that and its like its like when he starts seeing the curbs and you know I say dad you know you are missing the queues here. So, it, I just know from my experience and my you know my education in training that driving is such a uhh... primary value for anyone... Because it really symbolizes independence and its it symbolizes I can go where I want and I don't have limitation and I don't have dependency on other people to do that so umm..." "I said well my dad's a mason. He's like 70-some years in Masonic... And there is one of the two Masonic lodge is in Springfield, so that was an option.. But this other place called Oakwood, which was newer and seemed a better fit for him. The reason being that the Masonic home is full of Masons from all over Ohio and my father had a jewelry store in Springfield for 50 years and this place is full of people who knew him then and knew that and were part of that old kind of alter. So he's known... Yeah, so that he gets that kinds of support, that kind of social support as superficial as it is but its there... Or someone will say, 'you see this diamond ring I bought it at your store 50 years ago.'" "Right, exactly and he knows people from other things so yeah that's really sort of priceless. You can't get that and I just know in terms of</p>
	ZOEY.32.5-32.7; 32.26-32.27; 33.3-33.	
	JIM.14.16-14.20; 15.14; 16.8-16.9; 17.20-17.23; 53.1; 54.5-54.8, 54.14	
	BO.12.19-12.25; 13.1-13.12	
	STEVIE.14.2-14.8; 26.19=26.21; 31.9-31.14; 44.13-44.23	
	MAC.2.17-2.20; 12.20-12.23; 25.6; 46.6; 6.17-6.18; 47.5-47.20; 26.10; 13.4-13.5	
	ERIKA.1.21-1.25; 2.4-2.23; 3.5-3.8; 32.28-32.35; 16.32; 17.1; 48.13 -48.28; 49.9 -49.12; 49.23 -49.26; 50.1 -50.2; 59.9 -59.17; 60.22 -60.27; 67.17 -67.31	
	PATRICK.2.3 -2.11; 3.10; 4..2 -4.4	
	SHARON.7.14-	

	<p>7.23; 8.1-8.23; 10.5-10.6-10.26; 11.7-11.11; 14.7-14.12; 16.5; 17.6-17.7; 82.23-82.24</p> <p>KEVIN.3.8-3.11; 4.20-4.25; 5.1-5.5; 9.7-9.9; 10.2-10.13;50.24</p>	<p>anecdotal people go to Florida and you know they go they 6 or 8 people will go down you've got so many people who will go down by themselves and its awful its just awful... Well that's why they call it God's waiting room " JIM</p> <p>"he floated about for about 2 years so maybe he has been there for eight years. I mean it is curious that it has been that long but he's fit in very well. He is very applicable, very sociable, you know unfortunately his wife's not there and it became very apparent to myself I mean anyone around him, my brothers and I in particular that my, how important my mom was in his life... she saw that things got done and she was the social organizer" "they were partners in the true sense of the word but she had her outgoing stuff that she ran and he was happy to come along and be sociable and it was organized and it was fun and they had a great life together... Well, not only did she pass away in February during the hurricane season their condominium on the 32 floor of the building where they lived in Florida West Palm beach got hit within a week by two different hurricanes. So he not only lost his wife but then he also lost where he lived" BO</p> <p>"Some of us think that might just be enabling her or spoiling her. She's this helpless individual really. She has always been this dependent type. So we feel like 'no' my other brother is like no we can really put our foot down and say 'no mom you have to help yourself you have this condition' during her lucid moments 'why don't you rise above it.' While she's lucid not when she gets into this whole spiraling down but when she is aware let her take ownership of the condition and help her help us." "Because once they start feeling helpless, granted she is not the independent person but there is still some you know some sense of 'I can make decisions for myself' and once you rob her of that than she will just feel like a vegetable." "we all agreed that maybe she should get into some charitable project in the Philippines so when she does a random act of kindness it gets her involved. We are working on that umm right now I think my... back in the Philippines she attended this dance class once a week stuff like that but I haven't really thought of when she comes back here to visit what project we would do" "for instance I always was so proud of her, she could hold her own she was so social. I remember at my wedding in the rehearsal dinner, I revered her so much. I talked about how great she was and then now I am thinking like things like: do I shush her when she is saying something embarrassing; if she doesn't fix herself will I be embarrassed for her; just little thing that I don't want to feel but will come out...Or I called her own time in Manila and she just wasn't herself I could see in her face she just wasn't her best self. Basically I said 'mom that's not you. I know you fix yourself so well' but she just was not into it. I remember thinking oh I don't want people to see her when she's like this" STEVIE</p> <p>"That's her home. She has seven children so she visits us. She has a couple here, that's me and Stevie. Sister in LA, a brother in Canada... And then the remaining siblings are still in the Philippines" "So [the Philippines families] are starting to have a little more but I digress. So coming over here, in that setting you have my mom who comes over here who is set in the old ways. So here she is helping wash dishes.</p>
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		<p>She is trying to be helpful in the house because she knows there are no maids.” “[Mom] doesn’t have a permanent place.” “No she lives with my, she doesn’t have a home anymore so she lives with my brother” “I said when she was with me when she would visit me I would notice the forgetfulness” “So lets bring her to the States. That’s when we asked her to come here. She was here the longest when I applied for her green card. I told her she couldn’t go home until she got it. She got it in like eight months... Now she, I told her just don’t ever let her stay there because it might get worse. So she ended up staying with Gbrother when she went back ... Right and now after many years ... No she wasn’t she wasn’t okay with that. She kind of felt hurt... Yeah and uh so in retrospect mom was kind of living out of a suitcase” “Uh so seven kids and [mom] stays mostly in the Philippines and visits all of us” “Yeah, its changed for her to see us okay... kids in America they are different they are expressive but the household here because she knows she is visiting” MAC</p> <p>"Because in the beginning she would watch TV in her room and it seemed to be company but then as the dementia got worse, she didn't even know what the TV was for." "Because of the hearing problem. That in itself I have read that that in itself could cause people to withdraw because they're cut off from their world. And when you can't hear conversations in the room um and what she suspected is that we were always talking about her and she would say at dinner I think I'll just go to my room. And I'd say why mom and she'd say I just don't like you talking about me. And I'd go we're not talking about you, I'm talking about work. You know and so that withdrawal and that kind of paranoia thing. The little wall that went up that was dreadful." "in the beginning she would watch TV in her room and it seemed to be company but then as the dementia got worse, she didn't even know what the TV was for ... So she couldn't follow a TV program. We would bring her out here with us in the evening to watch TV but a lot of people in their upper 80's have hearing problems as well. And so she would want the TV blasting ... And we really couldn't have it and so we got her these TV earphones and she wouldn't wear them so. So it was hard to integrate her into our family life" "Unless you speak loud and into her good ear, she really couldn't converse or understand. So we had this party but I was thinking you know what did she really get out of it" "Had she had a career or if she volunteered somewhere. You know after my dad died. I was like so helping on getting her involved in something. I remember calling one of the agencies and I thought my mom would be great teaching little kids how to read... And the woman said to me. You know it's very nice that you're making this call but your mother is the one that needs to call us" "Yeah, and all she wanted to do was go home." "But the more she figured it out that that's where she was going to live. She was .. she was not happy." "Well when we'd come to visit, you know.. She would appear to be fine in the lobby, you know like with all the other people sitting. And I would come and say, Hi mom! How are you doing? And she'd say did you come to take me home?" "And she said well, where am I gonna go? And I said we'll you're gonna go back to your room. She says, I don't have a room here. And I said, well mom you do and it's a lovely room. And then she got really nasty. She said I don't like what you guys are doing. And I don't like the way you're doing it. And she said I'm not going in there.</p>
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		<p>And if you make me go in there, I'm going to kill myself. She would get mad at me. And at one point she said, well if this is the way it is, I wish I had a gun and I would just shoot myself. And I had called her doctor the next day. And I think every family needs to have a geriatric psychiatrist because the only way to cope with this is to balance the medications. Make them just sort of okay with it. Because if they're aware of how their brain is going, you'd want to kill yourself." "That was her life. That was her life. And living here was not her life." " And she says I don't wanna.. I don't wanna.. I don't wanna be with people I don't know. And I said well you don't know them now but you could get to know them." "My mother has all these medicines that are keeping her alive and she's 90 and here she is. And my mom didn't want to. She didn't want to move in." ERIKA</p> <p>"she was living by herself. She couldn't stay there. She wasn't eating right, she has diabetes, we caught her well we found her in a state of extreme low sugar levels obviously indicating that she is not eating properly." PATRICK</p> <p>"He..., they took away his keys. He stopped driving... That was probably 4 years ago... Three and a half, 4 years ago... Umm, well there was an incident where he backed out of the driveway and he backed off the driveway.. and he backed onto the side of the driveway and broke an axle and it was a whole big" "Whole big thing and he didn't remember doing it... He kind of, he just fluffed it off, he didn't think it was a big deal, didn't remember doing it, didn't know. So it was kind of suspect cause my dad, he's always been kind of a...offensive driver... It's his way. Get out of my way. I know what I'm doing ... So that was kind of a clue that something was not right .. Always aware ... Yeah, always knew what he was doing. I didn't exactly want to ride with him. (Laughter) But he knew what he was doing most of the time. So when that happened, my mom, after that happened, she started noticing getting worse. He was just becoming forgetful..... And he was kind of ...uninvolved ... Yeah, withdrawn ..." "he just kept getting more and more withdrawn. He stopped going to bed on time and started sleeping and sleeping and wandering all thru the house... He. Or it was Thanksgiving of 2012, he got up and left the house and was wandering outside... Yeah, wandering outside ... [Mom] called me, 'can you come now cause dad's outside walking in the backyard and the neighbors saw him,' cause he never left the house... He was always, my mom would, he always sat in this one chair in the living room watched the History channel all day, that's all he did all day. Never got up, never left ... Then one day he got up and left the house. So that was (something garbled)that something was wrong. So when I got there he was, he was sitting on the back steps by the back door with his coat on and his hat on and he couldn't tell me why he was sitting there. So I said, "What are you waiting for, Dad?" And he said, "I don't know. I'm just sitting here. I'm supposed to be doing something. I can't remember what I'm doing." "He was always saying that he couldn't remember what he was supposed to be doing. That's a recurring question with him.....to this day" "I: And was your dad there, too?... S: No..He'd be at the house and she'd have a friend of hers stay.....so he wouldn't be by himself"" "He, we tried to get him to take a shower (something garbled).</p>
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		<p>He wouldn't" "...he doesn't see it as that, he must see it as getting in the way or, I don't know, I don't really understand that point." "Then he just stayed. He got used to it and now we don't take him out to the house. Like he doesn't come over. Even for holidays" SHARON</p> <p>"He was sleeping a lot....Yeah, yeah. He was disconnecting. Disengaging. It was a gradual thing. It wasn't one big there you go. It was more... the more you saw him... because I didn't see him everyday. You would notice things if you would see someone everyday. So, that looks a little different" "Uhhh, it's very, um, disconcerting. It's disengaged. Yeah, because it's, it's hard to make the drive from Kirtland out to Avon. Because I know that's it's not like I'm going to visit someone that I'm going to have a conversation with... I'm going to talk to... I'm going to sit with somebody who kind of recognizes me, but there's no conversation. I bring up things like Benedictine. Things like football and... Benedictine, and sports. And, he's not even keeping track of sports anymore, so... There aren't very many topics that I can bring up that'll.... That we'll have a good conversation with. So, it's more I'm sitting, I feel like I'm sitting next to a stranger" "77/78. Yeah. And, he's a bigger guy, so getting him around became a lot and he just just withdrew and he didn't want to do it anymore. I pushed him a few times, but I never pushed him enough to make him go. I just said, ok" "And, we'd all be there, or whoever was in town, and, uh, my dad would sit in his chair in the tv room, and he would be disengaged. Everybody would come and sit with him, but he felt, um, uh, disengaged, displaced. Like, not, not part of the group. And, we never made him feel... He withdrew himself." "Disintegration" KEVIN</p>
9 Formal Care Resource or Another Problem? (Microsystem)	<p>MATTHEW.8.15-8.17, 8.20; 9.3-9.7., 9.11-9.14</p> <p>ZOEY.5.6; 29.6-29.11; 44.6-44.7</p> <p>JIM.13.13-13.18; 60.24-60.25; 61.10-61.22; 62.1-62.5; 62.11-62.12; 26.6-26.7; 50.11-50.21; 51.1-51.3, 51.23-51.24</p> <p>BO.11.7-11.28; 15.20-15.24</p>	<p>"Things have changed dramatically since my mom moved to a dementia care facility. When she was living on her own, there was a lot more involvement by both me and my sister." "We're still in the early accommodating phases of her new living situation." "And so she was living there, and as her cognitive impairment increased we initially hired somebody to spend 2 or 3 half days a week with her, just very minimal. But to keep her company and help her do errands and that sort of stuff. And then that caregiving, hired caregiving help expanded, expanded, expanded over time until it was 24/7, still in her condo, still in her own home." "a year and five months prior to her moving to a dementia care facility. A year and five months was 24/7. Prior, I'd say the period in which the care increased was about a year and a half. So maybe the whole three years of steady decline. Three years of home care, and then institutional care."MATTHEW</p> <p>"Well certainly we're in touch with the staff on a regular basis" "In other words, when the decisions came to move her into a residential facility, she insisted she was fine..., and we were like what do you do? And we decided... and we decided that she did not have the capacity to assess her own level of safety." "My mom, well, she's in a first rate facility. It's exclusively dementia care. And the staff is specifically trained to care for dementia patients. They're just fabulous." ZOEY</p>

	<p>STEVIE.14.13-14.14; 36.19=36.24; 33.29; 36.3-36.8; 44.26-44.27</p> <p>MAC.13.17-13.22; 51.6-51.9; 53.2-53.4</p> <p>ERIKA.15.8-15.35; 16.1-16.2; 51.11-51.24; 53.1-53.2; 53.9-53.18; 57.30-57.30; 49.24=49.26; 62.19-62.23</p> <p>PATRICK. 37.22; 38.27-38.28; 39.3; 39.12 -39.14; 44.2 -44.3; 1.19 -1.20; 25.12 -25.22; 26.1 -26.25; 27.1 -27.3; 27.15; 27.24; 28.20 -28.21; 29.18 -29.31; 30.1 -30.10; 32.4 -32.16; 32.17 -32.30; 39.5 -39.10; 40.7 -40.10; 40.10 -40.28; 41.1 -41.4; 37.15 -37.29; 52.1 -52.22; 38.1 -38.24; 51.21 -51.25</p> <p>SHARON.3.18-3.22; 4.1; 4.5-4.25; 5.2; 5.8-5.20; 14.21-14.22; 15.4-15.6; 16.7-16.20; 42.3-42.13; 77.22-77.25; 78.4-78.29; 79.20; 83.29-83.30; 84.1-84.28</p>	<p>“[dad] he lives in a but its congregant housing... and they eat, if he wants, in a dining room or he can drive his car and go somewhere... Uhh, but they don’t serve Sunday meals in the evening so my dad goes out Sunday evening” “We have talked to my dad about if he were to require more help what the next step would be” “Umm... but what what when I thought about it was if he is in assisted living he should be in assisted living in that building... its called Oakwood... That he should be down the hall of where he is now... He has been there for an X amount of years. People know him there, he knows people there. Most importantly all his medical stuff is there.” “how do you create a whole medical- he’s got his skin doctor, he’s got his eye doctor, he’s got his general practitioner... They’re all right there, so yeah that’s, it’s like okay so it looks like that is where he is going to be.” “but actually I am going to ask them to put a grab bar on the front of the shower because sometimes its hard for him to get up.” “, I mean he is in a community that is supportive and he is in this kind of slipping kind of cognitive memory type” “he is part of this community... Right yeah so let me just give you a little synopsis of that. He lives in a uhh... he lives in an apartment., He has a parking space because he drives umm... he has breakfast; he makes his own breakfast everyday.. He has a little kitchenette yeah, a little kitchenette. Mostly stuff like cold cereal and yogurt with nuts...” “Yeah, he will have lunch in the dining room and he usually eats with there’s, the good thing about assisted living and congregant housing is it’s the worst of junior high school in terms of cliques of where people sit” “Uh, but that’s that’s kind of his living situation. There is uh... if you go down the hall far enough there is a nursing” JIM</p> <p>“his living situation particularly without mom and his new set up and where he is and come to the realization that where he is is a good place and it is a good place. It, for me, was a little of a shock because I’m thinking nursing home but it wasn’t a nursing home but initially it was just like, who are these old people” “So he’s in Springfield and he’s at a its Oakwood Village, it is run by Mercy Hospital, sister of Mercy people, I’m not sure which... so anyway they have these various wings and units. The nursing wing, the other wing... So he’s in Springfield and he’s at a its Oakwood Village, it is run by Mercy Hospital, sister of Mercy people, I’m not sure which... so anyway they have these various wings and units. The nursing wing, the other wing.. He has his own apartment, he has his own car, he drives, he grew up in this town, which initially I was like, what? And then I was like, ohhh he grew up here. He knows this town like the back of his hand plus he worked, he had a business there,” “That my brother RBrother’s wife and Jim pretty much did the walk thru and looked at a couple of places and this was, they felt was the best place for him in Springfield. It is a good place. They do provide very decent services. For what it is it is perfect for him though I wish he gotten a two bedroom there instead of a one bedroom” BO</p> <p>“We don’t know we said okay we are self medicating why don’t we try to educate ourselves and talk to professionals” “Well no no formal but I did tell my siblings back in Manila the next time they go to the</p>
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	KEVIN.47.4-47.8	<p>doctor to sit with the doctor and what your role as the children of someone with dementia would be. How could they be actively involved? Are there behavior modifications for us to monitor with my mom? How do we address her repetitiveness? That way the doctor involves us so that is not formal yet but that is the plan.” “Well she is a permanent resident so she had Medicaid” “when I was home we almost talked about actually hiring a caregiver. Someone who would listen to all her stories, make sure she takes her meds, someone who is trained to do that but we didn’t get to that. We thought maybe we could wait a little bit because my brother and my sister they also have young kids and they are so busy and they work. So even if they have help there the help is really just to take care of the house and not to take care of her.” “Do I have the courage to put her in a home? That is a totally different thing it’s a big no no for us.” “So the battle was to prove you qualify. And to keep some money coming in so my mother could live herself</p> <p>“STEVIE</p> <p>“I have been trying to get her to come here so that she can be with us too ... Plus medical wise it is more advanced here...Lots of opportunity for her to get the proper care but you know she wants to go back” “Yeah just pick up my mom and bring her to a friend doctor and we wouldn’t even know what’s going on. So I said ‘hey guys don’t get mad about that because that could be a big help because if we are all busy her older sister. They love her too so lets...’” “I: how is formal care involved with it because that is something in the United States...M: Nonexistent” MAC</p> <p>“And I called her doctor and I said my mom is not you know comfortable in this house and she doesn’t believe she’s in her house. And his nurse got on the phone with me and you know gave me all the little tests for stroke. Well she didn’t have a stroke... They wanted her .. Her interns came to the hospital, you know. And said well you know we can keep her overnight but she’s not going to have a bed in a room. She’s going to be in the hallway... But it was no point keeping her there. So her discharge papers said altered mental state” “That’s all it said. And I came home with this, altered mental state. Well what does that mean? What do I do about this? Um you know nobody said the word dementia. Nobody said anything” “Um and then there was a horrible medicine mistake... Well Dr. Frankel had changed her medicine to something .. it’s written in the other room. And the two spellings of the drugs are very similar . And the one that the pharmacy sent was like Yeah something very close. And so they started my mother on the wrong medication.. And one of the nurses somehow caught it because I don’t know how you would. Because the only way you could catch it would be from the original prescription to the pharmacy to see” “So that’s been an unfortunate thing that you know it was out of my hands you know. And you give up that control but .. but you know it turned out okay. She didn’t die from that” “Well it’s supportive to me because I don’t have to worry about it every day. Like I did it. I mean frankly she’s in someone else’s hands and they’re competent people there. Um, it’s just .. it’s a relief to me... I know. It’s expensive. And so we will. We will use up her money for this care. And if she’s eligible for Medicaid at that point, fine. If she isn’t, I don’t know what we’ll do” “So and you know the other thing</p>
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		<p>about some of these drugs is they are so expensive. I mean my mother's drug bill a month is almost \$600.00" "And I think every family needs to have a geriatric psychiatrist because the only way to cope with this is to balance the medications" Now there are Alzheimer's support groups. And I did seek that out...I did. And My Husband and I went to a meeting and you know people's stories in those rooms are you know very different and um one gentleman kept coming to the meetings even after his wife had passed away. He just .. he needed the support of that group of people" ERIKA</p> <p>"Sends a check, which is like five grand a month." "Yeah and now a regular nursing home where you are in a hospital bed and everything. Those are about nine thousand a month." " To keep the cost down she has a roommate now." "We saw one facility we went and looked at on the West side, really super nice and they had kitchenettes in them but it was a lot more expensive." "From the rest of us for what she did because we would have been spending you know five six grand a month that we didn't have to spend." "I don't know how long she's been in there... 9 months I think."s "And umm... so that's going on. That's getting bad so at some point, it is an assisted living facility, if at some point she keeps doing that there may come a time where she has to go into a different type of facility....Well she's in the memory care already. Yeah because that thing is all carpeted and you know they just put brand new carpeting in the place and it's not meant for people who are to the point, incontinent to the point where they are messing themselves up in front of everybody else there because some of the rooms you walk by and they smell like urine bad. Some people you walk by smell like urine. And they only give you a bath like once or twice a week." "They had given my mom, they were given my mom a pain medication and it should have been some other kind of medication. I don't know if Erika told you this. They were giving her the wrong medication for a couple of weeks." "They had her on Vicodin" "See and you don't know if she's getting her pills you know. "It seems to be different all the time. There is the day staff. That's the ones my sister if there is a problem we'll hear from Jackie or I forget the other ladies name. It seems like the staff changes there all the time so I can't get to know anybody and then there is new faces. .. I keep seeing different faces all the time. So I don't even know who is... how much consistency there is or how do you possibly know what all the special needs for all these different people are. They go on a computer screen every time they complete a task they are supposed to enter it you know. I see them going up there but we don't know the detail you just have to sort of trust you know that they're doing what they are supposed to be doing. It is a beautiful place; the food doesn't look too bad. We've had the food; we've been there for" "So but you know it is a safe environment she's not going to escape. It's locked you have to hit a code. She can't get out." "Yeah we're going to have to do it because I don't think they are doing it so... she was in physical therapy where they took her in like two or three days a week put her through some exercises but then that period runs out. She met whatever goal you know how they go to another" We had meetings with lawyers you know we had one lawyer that set up a trust for my mom and the money you go from this account first and deplete this one first before you go to the next one... "Right with this latest lawyer he says he can try to say that he can protect half of her assets." "Umm... well she has to be what</p>
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		<p>happens in most of these places is it is self pay for a year to three years depending on what facility you go into. You have to self-pay before Medicaid will kick in" "Yeah, now if you don't have anything than obviously you can... like most of these places these assisted living scenarios they umm... they'll have maybe out of 150 beds they'll have maybe 50 or 20 to 30 or something smaller proportion are Medicaid beds where people can come right in....It's a self-pay thing and you have to apply. You can't even apply for Medicaid until you meet the the requirement of that facility is a year or two. I think for this place it is two years self-pay...And then you have to hope that the timing is right and now there is going to be an opening, a Medicaid bed is going to open up for you because they are not all Medicaid because they make more money on the self-pay. And the nicer the facility the less Medicaid beds they have and the crummier places will have more Medicaid beds but they are crummier. You can tell by the staff you can tell by the facility as soon as you walk in there you know it is a little different standard of living." It used to be a three year look back now it is a seven year look back now so you have to have everything out of the parents name for I think it is seven years now for you to have a better shot of the state or Medicaid not getting it." PATRICK</p> <p>"He is in Avon Oaks.. In a facility.. Well, it's assisted living and there's a section that's memory care"</p> <p>"It's, ahh, I don't know." "Umm, it took us so long to get him somewhere.. You know, my mom, I mean we (something garbled). The lowest point was going to the a VA home in Sandusky because my dad's a veteran... Yeah, because it was such an institutional feeling to it. They take very good care of the veterans but still it's just like... It's like cattle coming in and out .. Yes, so in between there and Avon Oaks was a myriad of other facilities that she looked at, we looked at together. And my brother would go and we'd take turns. So I think she looked at 6 or 8 places and she settled on Avon Oaks because it was recommended from a friend of hers.....and it turned out to be fine.... But the thing is that when you're looking at these places you kind of lower your expectations so then you get in there and you see that they're really all the same..." "...the same kind of feeling, the same kind of carpet, the same way of treatment (garbled)..." "And the feeling of the place. And the people were very kind to her when she was touring there and answered all her questions and were very helpful and they helped her figure out Medicare ... It's a beast ... I mean it took her a year to just figure that out... Just to get situated. So the whole thing... So I'm okay with Avon Oaks and they take good care of him... I think my mom questions it sometimes but she doesn't want to" "I think we, there was,...some wanted him to go to the VA hospital in Sandusky cause he's a veteran and they'll take care of him" "Pretty much like 90 percent of it probably ... Yeah when most are like six-thousand dollars a month" "He will do it [take a shower] there...Umm, I think he, well, at this point he, well he reached a point where he would do what, he will do what they tell him because he's taking direction. He doesn't see them as not family. He sees this person as someone telling him what to do...He's okay with taking direction that way. He doesn't know what's going on or why he's there but if you tell him we're going to go down the hall and get some dinner, okay, We're going to go down the hall and take a shower, okay... So he does that. But he wouldn't listen to us" "he's</p>
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		<p>in a two-person room ... And the guy who shares with him is very nice. He doesn't have dementia. He's just bed-ridden .. So my dad was really in an Alzheimer's unit but my mom decided to take him out because the rooming situation was awful. And so a room opened up in another wing of the facility but it's not dementia but it's care anyway so.....so he's in a better wing where people are more lively. So his roommate is, he's a great guy. We have long conversations about cars when I go in there. (laughter) He's a really nice guy" "Umm, it's very, they're very helpful people. They answer all her questions. They've been very in tune with what she wants for him. What she thinks she needs, there's doctors on call all the time and there's nurses always there and there's always people checking on him. He was in the dementia unit, he was the most high-functioning. So they loved him." "so the nurses, it was thru this care conference nurse manager that we approached the idea of having him moved out...(something garbled) room in the same building, just a different unit. And they then, I can't really speak to the day-to-day that goes on as far as his care and what he does , three meals a day and he's constantly taken down and he gets a shave and a haircut so we, and they bathe him every day and the doctors are always checking on him. And she can make arrangements for him, any additional care that she thinks he needs. Like he gets his eyes checked... Well, when he first got there, they made a memory box for him, two boxes in his room. And they're, they're really, really nice...one is a box that contains a listing of his life, you know, it's like a couple of paragraphs about his life and that's in one box, a wood box with a glass cover" "They really answer to my mom." "Well, umm, my mom did 90 percent of it. We just kind of listened to her and tried to help on the peripheral. But basically it comes down to. They're very few people who, I don't know, in my mom's world you can't afford to put someone in a home and directly pay, which is 5 or 6 thousand a month...So you're alternative is to keep the person at home and take care of them yourself and bring home health care in, which was an option. She investigated that or you go and take your case to Medicare and they have co-pay or but the fact that my father is a veteran, didn't really help.. So the battle was to prove you qualify. And to keep some money coming in so my mother could live herself" SHARON</p> <p>"K: He's in a nursing home... It's Avon Oaks in Avon... I: Do you know about any of the formal care that's going on there... K: No, not much. Nothing I can say with any certainty. No that's it" KEVIN</p>
10 Life Events as Catalyst for Dementia in Parent (Mesosystem)	<p>MATTHEW.11.33-11.34; 12.2-12.13, 12.27-12.31</p> <p>ZOEY.3.24-3.25</p> <p>JIM.15.20-15.22; 16.13-16.21; 36.2</p> <p>BO.13.9-13.12,</p>	<p>"I'll just tell you, we had an incident down in FL... my parents were both snowbirds for many years, and the year my dad died, um... In 2008 – two years in February... and he was ill before that, so clearly my parents did not go to FL that year. But the next year, my mom resumed going to FL for the winter.... So my sister and I went down to visit her at Christmas, or something like that, and we're driving, and we're in the car, and my mother is obstinately not putting on her seatbelt. Like a toddler would refuse... because my mom was just being so obstinate about putting on her seatbelt and eventually she got the message... There are so many ways in which it's like toddler-hood all over again." MATTHEW</p> <p>"Yes, she began to exhibit a little confusion, and you know, probably for a number of months we just</p>

	<p>13.20-13.24; 14.4-14.6</p> <p>STEVIE.7.15-7.22; 7.23-7.28; 8.8-8.19</p> <p>MAC.1.26-1.27; 3.20-3.22</p> <p>ERIKA.13.19-13.29; 13.33-13.34; 14.1-14.5; 14.17-14.18</p> <p>PATRICK.3.1-3.5</p> <p>SHARON.9.4-9.14; 12.1; 12.21</p> <p>KEVIN.10.19-10.24</p>	<p>attributed it to my dad's passing." ZOEY</p> <p>"[Mom] died down there in Florida....Umm, and then he, it was, there were a number of traumas at that time in addition to her death. Within 9 months I think there were two hurricanes that went basically right through, once literally through his condo" "[Rbrother and I] were both down there umm and drove at one point, 7 or 8 years ago, we said you know, we got of his stuff and are coming back to Springfield, Ohio because he was down there but he wasn't doing anything. It seemed like it was just depressing to me" "We were all in shock and so we just sort of did what we needed to do" JIM</p> <p>"Well, not only did she pass away in February during the hurricane season their condominium on the 32 floor of the building where they lived in Florida West Palm beach got hit within a week by two different hurricanes. So he not only lost his wife but then he also lost where he lived" "well we communicated on the phone but you know who knows. So it turned out he was living with friends, maybe over staying his stay, I know and since my mom wasn't around to like give him a sort of a compass, a social compass or a queue to what's right and what's wrong you know he's just doing what he thinks is right. So he eventually got a place, rented a place down there. It was a real mess." "Yeah right after, it was pretty obvious right after she left and umm now it is a different situation and he's 10 years older, he's 96 and he's health is going down. So we're all involved to try and keep him in a good state of mind" BO</p> <p>"And then she was heartbroken and she went into a deep depression. At first we thought it was amusing it was like a teenager. She didn't want to get out of her room, didn't feel like eating, very like so.. She wasn't even as depressed as this individual and I don't want to get into details but it turns out just from doctors and everyone who has given their professional advice that perhaps it was a trigger of what was to be this official diagnosis of dementia." "We don't know if she was already undergoing this dementia and a relationship that required intensity exacerbated it so when it didn't work out it just full blown or the other way around. She was just going through life normal and then the break up, which would be very normal teenager, would just feel really bad about it. At her age not feeling rejection what so ever it just kind of triggered the depression. So we don't know which was first" "So when she went through that break up it was like she was not herself in a sense. She did not get up to go to mass. She would rather stay in her room so we were worried about that. We all said 'once mom does not put make up on that is a bad sign.'" STEVIE</p> <p>"It is hard to say but I would say a year and a half ago. We just thought you know with age comes forgetfulness" "for example, she had broken up with a boyfriend. When my dad died she met somebody and they broke off. It's been a year but she thinks it was last week and she was calling the boyfriend for example" MAC</p>
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		<p>“And when this occurred. Because I didn’t know anything about it except that I came to the hospital. I visited her everyday because she was in Geauga Hospital. And the morning I came, the nurse kind of stopped me in the hallway and said, your mom ripped out all of her IV’s last night. She’s really upset. I was literally trembling because I did not know what was going on. And I had thought it was something to do with her diabetes that she you know I said maybe she has low blood sugar. Are you monitoring her sugar because I did it religiously you know. And I noticed when she was in the hospital they weren’t.. They had other fish to fry. I mean they had to fix her ulcer, I understand that but I was concerned that this behavior was caused by a drop in blood sugar... But in fact from what I read Sundowners Syndrome is a behavior that shows itself before dementia or part of dementia development.” “And then maybe a couple of years later she had an episode where she wasn’t eating regularly enough. And her blood sugar dropped and by the time Patrick got to the house because my niece was talking to her on the phone and ... long distance and my mother’s speech was slurred. And she called her dad, Patrick, and said there’s something wrong with grandma. Patrick went over there. She was slouched in her chair. And she was clearly slipping into a diabetic coma. He calls the squad. They take her to the hospital. So she’s in Parma Hospital and of course as soon as they ran the you know IV, the glucose, she kind of snapped to it” “So you know this kind of behavior started and it was probably precipitated by the you know the diabetic crisis” ERIKA</p> <p>“Living by herself and it was a slow steady progress of you know somebody had to go over there and help clean and we took her shopping and doctor appointment. We would take turns doing that and it just got steadily more problematic with her issues, you know?” PATRICK</p> <p>“And then things just kind of progressed. And then, it must be two years ago, he took a bad fall in the living room while he was sitting on the computer chair... And my mom thought he had a stroke... Turns out, he didn’t... He was fine. Nothing was wrong. Went to the doctor. And all that stuff. But she really thought that’s when it all started...” “So it was just, things just started building... Cause he’s, got a lot of issues going on. He has diabetes. He has diverticulitis” SHARON</p>
11 Role Reversal (Mesosystem)	<p>MATTHEW.11.22-11.31; 12.13-12.14</p> <p>ZOEY.1.32; 2.2-2.3</p> <p>JIM.70.19-70.23; 71.2-71.3; 17.20-17.23; 18.2-18.326.19-26.20; 27.9-27.11</p>	<p>“Dealing with my mom in her dementia is so reminiscent to me dealing with my kids as toddlers. Totally. It just comes all the way back around, and my mom, in so many ways is functioning – and I don’t mean mentally – but emotionally she’s functioning at the level of a three, four, five, or six year old, I mean to the point, to the point that there are some differences, like I remember telling my kids, like “now we’re going somewhere and you have to go get into the car, ‘cause we’re going somewhere. And if a child doesn’t want to do that, you can pick them up and put them into the car seat, buckle them into the car seat, and then they go along with it. My mom is in the same state, except I can’t pick her up and put her in the car! So I say “Mom, now we’re going to blah, blah, blah, and put on your seatbelt.” MATTHEW</p> <p>“Um, I would say [snickering} that I worry about my mom. That’s a big ... Um... eight hours a day. Um,</p>

	<p>BO.13.25-13.30; 54.18-54.26; 66.22- 66.25</p> <p>STEVIE.7.15-7.22; 27.21-27.28</p> <p>MAC.8.4-8.12</p> <p>ERIKA.1.27-1.28; 12.27-12.36; 41.14- 41.33; 65.23-65.31</p> <p>PATRICK. 1.8 - 1.16; 4.2; 21.29 - 21.30; 22.1 -22.8; 31.11 -31.30; 2.3- 2.11; 3.10; 4.2-4.4; 31.4-31.18; 44.23 - 44.36; 45.19 -45.24; 46.5 -46.27; 47.1 - 47.31; 48.1 -48.16</p> <p>SHARON. 16.7- 16.20; 83.4-83.9</p> <p>KEVIN.</p>	<p>I spend time trying to think of things [Fraggle the dog whimpers] that will engage her attention when I go to visit. It's like making a lesson plan." ZOEY</p> <p>"the it's the biggest burden is to get him to behave himself... To continue to behave himself and to in a sense parent him in a way in sort of a delicate manner" "Right or just to... well it's being honest with him but as if I am lecturing him to not lecture him." "Its novelty and it is new stuff that is so difficult to deal with. So I told him, I don't want him on the highway and I don't want him to drive at night. I said, dad, I say this to him every time, if there is an accident you will be to blame because you are 95. It's as simple as that" "you are a great driver, you have always been a good driver but if you get into an accident it will be your fault and you should just be aware of that." "my dad is on the sucker's mailing list and that happens. I say dad ..." "I walk him through that and I talk to him, if they want money, if they want a survey, and if they are trying to influence you with children or animals or veterans throw it away" JIM</p> <p>"you know we were all sort of involved but Jim particularly because my dad seems to, since Jim is the eldest, he seems to fall in line with the most of my father. I mean they apparently have a very good relationship and my father at this point anyway looks to my brother for advice or would rather give him things to do. I mean since my mom is not there, I mean my mom really provided a lot of support for him" "Jim called me last night, Jim and I talk and he'll send an email or something because sometimes my dad does some stupid things because he is 96 and people are always trying to take advantage of him because he is old. There was something that he did, he sent a check to somebody for some supplement and Jim's freaking out because like, I don't know if this first of all what it is and if it's going to interact with what he's taking. So he said, RBrother I'd like you to go over there tomorrow and get this and get it out of there and Jim never heard from him, he sent him an email and never heard from RBrother, didn't hear." "we said look dad we don't want you driving on the freeway. As you taught us to drive you know things happen to quickly and especially today there is way too much and we just don't want you doing this and more recently in the past year we don't want you driving at night" BO</p> <p>"And then she was heartbroken and she went into a deep depression. At first we thought it was amusing it was like a teenager. She didn't want to get out of her room, didn't feel like eating, very like so.. She wasn't even as depressed as this individual and I don't want to get into details but it turns out just from doctors and everyone who has given their professional advice that perhaps it was a trigger of what was to be this official diagnosis of dementia." "And yeah but [Gbrother is] the type of guy, you see it as young children, he would set goals, he would have illustration boards, visualize. He will use all these techniques and strategies like you know how to have her walk with the kids, watch their activity. So he has all these, he is a very creative person. He has all these great ideas about goals or visualizing or steps to getting to your goal but maybe that's why it frustrates him. He is trying to handle my mom in this very.. Structured and boards and visuals you know" STEVIE</p>
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		<p>“Oh yeah I remember one occasion, which I brought up with them. I remember this... my mom was making her favorite or my favorite chicken curry with cornflakes... After that she starts liking her fingers... I go, I kind of yelled at her, ‘mom what are you doing? You could get salmonella...I mean come on that is the first rule in the kitchen.” MAC</p> <p>“So right now I’m not caring for her but when she was living here you know she was like having a toddler. You know it was 24/7” “No so she never... So I could never help my mom get to where I wanted her to be” “we didn’t trust her on the steps so we had to put a gate at the top of the stairs and then I was doing her laundry every Wednesday. Because her arthritis was getting worse.” “Um you know when she was here it was you know I always had to be thinking about stuff for her ... You know so it limited .. our meals... Our meals and you know it was just. She had to be my first consideration because she was the one that needed the most help. And so you know as a daughter and as a mother you think of yourself last.” “It is. It is. Um one of the things that came out from my mother’s dementia is they lose their tact or their diplomacy. They say whatever’s on their mind.” ERIKA</p> <p>“We don’t call she probably wouldn’t even know how to use a phone or we don’t want to even give her access to a phone umm... we would be afraid she would be calling, especially my sister, bothering her at all hours of the night and we don’t want that to happen so...” “Yeah and as my mom got sick she would let her feelings that you would usually keep inward she would blurt them out.” “Yeah, she was kind of out of it” “You stop walking and you are going to get worse and worse and worse. ‘Yeah I know I should do it’ well then why do you complain?” “But she fell either trying to get on or off the toilet so she needs help every time she goes to the bathroom now.” “she was living by herself. She couldn’t stay there. She wasn’t eating right, she has diabetes, we caught her well we found her in a state of extreme low sugar levels obviously indicating that she is not eating properly.” “when they get older they are like little children and my sister used to try and get my mom to walk more and do exercises. Well then she’s the bad person, it’s like just not happy and the disciplinarian like and then Erika would get the brunt of everything.” “In the last...No she’s pretty much in a wheelchair the last month and a half she is in a wheelchair and I can tell her ‘Mom lets go walk in the walker for a while’ and she doesn’t want to do it.” “Its aggravating, love my mom to death but when it is ‘what? What? What?’ you know complaining about you know umm... you know it is aggravating to have a person with dementia living with them. Love my mom to death but they get they get like little kids but then the hearing ‘what? What?’ She always did this to my sister ‘What are you talking about?’ We’re not talking about we’re talking about this and you have to explain yourself all the time.” “Oh getting her up in the morning oh my god it’s a process. She is so hard to get out of bed. My sister goes ‘you have to start two hours early before you’re going to leave because she is so slow.’ You have to physically go ‘mom you have to get up’ every ten minutes go in there ‘mom you got to get up mom I’m not leaving get up.’ You know fight with her ‘mom here’s the</p>
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		<p>toothbrush' you know 'okay I'll do it in a minute' 'no mom you got to do it right now.'" PATRICK</p> <p>"He will do it [take a shower] there... Umm, I think he, well, at this point he, well he reached a point where he would do what, he will do what they tell him because he's taking direction. He doesn't see them as not family. He sees this person as someone telling him what to do... He's okay with taking direction that way. He doesn't know what's going on or why he's there but if you tell him we're going to go down the hall and get some dinner, okay, We're going to go down the hall and take a shower, okay... So he does that. But he wouldn't listen to us" "We took him out for some holiday last year, hmm, maybe July 4th or something, I don't remember. But it was a struggle, we were glad to take him out of the home and we got him to the house and put him in the (cedar?) room and gave him his movie and the remote and thought that it would be okay and then it wasn't. He didn't know where he was. He was just there. He followed directions. We made him a plate and we sat with him and he didn't understand what was going on and it was just really..." SHARON</p> <p>"But, we couldn't tell if he was just unhappy, or... Or, if he was just tired, or didn't want to deal with us all, or... uh... We just thought he was cranky old man" KEVIN</p>
Relationships that Carry Individuals (External)		
12 Roles Through the Years (Mesosystem and Exosystem)	<p>MATTHEW.17.1-17.2, 17.12-17.14, 17.20-17.21, 17.25-17.26; 18.21-18.22; 29.28-29.31; 30.1, 30.14-30.17</p> <p>ZOEY.25.5-25.7; 7.3-7.4; 8.2-8.3; 11.12-11.13; 8.7, 8.21-8.22, 8.27</p> <p>JIM.1.20; 9.19; 11.18-11.23; 36.12-36.16; 63.1-63.5, 63.11; 30.17-30.18; 41.15-41.16; 31.21-31.22; 40.85; 56.24-56.25</p> <p>BO.13.1-13.3; 13.24-13.30; 14.17-</p>	<p>"Well I think we've been... yeah... our lives have followed somewhat similar tracks. Um, we uh [laughing] without getting too much into the nuclear family phase of life... Well, it was. We had a good life and so forth. And my sister and I were sort of just, you know, we got along fine. You know we were far enough apart that we weren't in each other's faces, um... Um, but then we reconnected in young adulthood or sort of found one another again. And I don't know we just reconnected, we liked one another... We were sort of moving along in the same path..." "The relationship has always been there all along, and it's available to each of us. Dealing with our mom's, as you say, cognitive decline. You know that's just the latest chapter in something else we're both sharing" "But I think. I mean we look for it in other relationships. And in my sister's case, she married a guy that you thought – not thought – that she felt would allow her to achieve in her marriage what she did not achieve in her relationship with my mom, mother and dad to a lesser extent. But my mother in particular. But guess what? The man she married was even more limited than our mother." "We have talked about this, that's specifically why she married him and why she stayed with him all those years because she was going to get through to the other side, that she had never been able to get through with her mother with her husband. Now that was never going to happen." MATTHEW</p> <p>"If you understand my mother's background, you have to have a great deal of empathy for her, even while she's kicking you in the head." "and as a consequence I think fundamentally she never really trusted people, and she had a great deal of difficulty with intimate relationships" "but my dad was extremely social and gregarious. He sort of filled that gap. So she was in charge of the intellectual stimulation in the</p>

<p>14.18; 28.22; 14.9-14.18; 54.8-54.10; 19.9; 44.1-44.4; 20.6</p> <p>STEVIE.20.29-20.31; 34.23-34.28; 40.18-40.19</p> <p>MAC.10.12-10.13; 35.4-35.14; 35.28; 36.2-36.3; 37.17-37.28; 38.6-38.7; 38.15</p> <p>ERIKA. 25.25 - 25.31; 32.14-32.24; 41.18-41.20; 42.2-42.19</p> <p>PATRICK.10.1-10.2; 11.21; 16.9-16.23; 18.18 -18.23; 15.; 19.6-19.16; 18.12-18.16; 16.21 - 16.25; 17.1 -17.4; 17.10 -17.15; 18.2-18.8</p> <p>SHARON.8.22-8.23; 11.18-11.21; 25.13; 29.7-29.9; 35.8; 47.14-47.15; 48.17-48.18; 49.19-49.24; 50.4-50.6; 50.26-50.28; 51.4-51.5; 51.27-51.28; 52.2-52.6; 52.12-52.20; 57.9; 62.1-62.18; 63.4; 63.6-63.7; 63.11-63.14;</p>	<p>family. He provided the emotional support in the family” “On the other hand, she never nurtured me once in my whole life. She was pissed off at having to be responsible for me.” “The way I like to say it is that my dad saved my life.” “my brother was – I love my brother – was flawless in my mother’s eyes... He ran interference for me from the time I was tiny. And I felt I could always trust him, and that he would always be there for me.” ZOEY</p> <p>“I’m number one; I’m the most responsible one” “RBrother is the middle son. So I am the oldest and RBrother is the middle “ “I: how he kind of perceived RBrother and or Bo. Like what, how do you think he saw them and their roles... J: Well, I think it has to do with career path and sort of adulthood and my... I had a pretty, I was a high school teacher, I got tenure, I left that I became a psychologist” “[Bo] he’s he has a very artistic uhh sort of temperament... And and we have a very similar, my brother Bo and I have a very similar worldview and perceptual aesthetic... My brother RBrother is very concrete” “You know it is always two against one.. I think you know, RBrother said we used to beat the heck out of Bo” “I’m the big brother...yeah” “my dad trusts me the most. It’s really simple, cause you know I will say, ‘ you know RBrother can do this’ and he’ll say, ‘he’s busy” “Well when we were growing up we did a lot of stuff together. We always did stuff together.” “I think it started off about 5 or 6 years ago when he said ‘I need a secretary’ and I said, ‘that’s because mom did all that stuff for you.’ “Anyways, so umm that RBrother has never worked for anybody else so that is part of it” “There’s this part that is just and it may speak to a larger sort of disengagement in the world [for Rbrother], I don’t know” JIM</p> <p>“[Mom and Dad] were partners in the true sense of the word but she had her outgoing stuff that she ran and he was happy to come along and be sociable and it was organized and it was fun and they had a great life together “ “I mean I call [Dad] or I go over. He appreciates phone calls and yeah all that. He always enjoys me coming over and it’s a good thing. I have a really good relationship with him.. And I always have actually. I mean I can’t think of a time when I have not had a good relationship” “ Jim, my oldest brother, you know we were all sort of involved but Jim particularly because my dad seems to, since Jim is the eldest, he seems to fall in line with the most of my father. I mean they apparently have a very good relationship and my father at this point anyway looks to my brother for advice or would rather give him things to do. I mean since my mom is not there, I mean my mom really provided a lot of support for him” “I mean [Dad] will talk to us individually or as a group has the same message basically” “. So we would like we would have these summits is what I called them. I’d have minutes and I’d have me laptop” “I: But you aid, so you guys are all sort of involved in that since your mom passed away but your but it seems like Jim your dad kind of defers to him. B: Well he does but no I I think that is more a recent thing but he always has to some degree” “I mean he will talk to us individually or as a group has the same message basically” “. I don’t want to speak for my brother Jim, we’ve talked about this and we still can’t we have a hard time understanding the connection with RBrother and my father even though he lives in</p>
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	<p>63.21-63.23; 70.8-70.18</p> <p>KEVIN.1.26-1.27; 2.1-2.9; 3.21-3.23; 6.14-6.19; 6.25; 7.1-7.15-7.24; 8.1-8.2; 8.15-8.16; 10.10-10.13; 17.6-17.7; 18.3-18.20; 23.21-23.23</p>	<p>that town. He lives three miles from him its...” “So anyway, I... Jim’s the oldest, RBrother’s the middle child, and I’m the baby” “. I felt I mean I guess my parents must have decided to give my mom, mom would have Sundays off or Sunday mornings because we, my father and the three boys would typical often go down to Yellow Springs and go to Clifton Gorge or go hiking in Plant Helen “ “I said black [Rbrother] said white” BO</p> <p>“Including my mom they were five sisters. My mom is the second among five sisters just to give you an idea of how they grew up. They grew up with a closely nit conservative Pilipino Spanish family” “Well going back to our norm, our culture how we were raised, there is all this politeness until she told me oh my god I was just not sensitive enough to know that and then she said ‘well we need to talk about it again.’ We always wait for the last minute instead of anticipating. Like me being the eldest sister I should have known that she was spending that much but she doesn’t say anything until the last minute so there is again this whole diplomacy, which is really becoming a barrier” “When you think about why are we so close it is because the challenges started early on in life so we had to grow up fast” STEVIE</p> <p>“We were spoiled because its not uncommon for a family like us to hire another family to live with us” “Well they say I look like my dad and then being one of the older ones when we were going through our own dynamics. Growing up we had our own financial problems even if we were growing up like kings and princesses.. Yeah so but I was more aware since among the seven I was number to and my older brother. My older brother and I would say we were the ones who absorbed a lot of it for the younger ones.. Yeah I guess yeah or just the fact that we were old enough to understand better what was going on” “Yeah I’m like my dad more. More like my dad in the sense values wise.” “Umm minus the drinking and the smoking. He was a family man as you can see I have seven kids” “I was like the ugly duckling I guess... More Asian looking I guess. I look different now. I look more Japanese now so yeah. My mom was more like when I was younger I was more like the, how do you say? I was taller than my older brother, I was bigger, I was more into the martial arts sports...So I was kind of you know the kind of guy the child that was more like how do you say? I guess it is better to describe this way, if my other brothers and sisters were treated more like children and I was treated more like an adult” “Or ‘you entertain the other person.’ She wouldn’t ask Stevie. You know the kid is here go take them out. I was more easy to say yes.” “Instead, well my older brother was doing his own thing most of the time” MAC</p> <p>"When we were little, I wasn’t even aware of it. I mean it happened when they were older and like I say, you know we’re all four years apart. So like when I was 18 and leaving, they were 14 and 12. So they went through high school and middle school without me in the picture. So I really wasn’t aware that they had these little things going on. So, and then Patrick became a policeman okay. And KBrother thought that Patrick became a policeman because he liked the power of the role." “And whenever the boys would come home, they would just give a grunt for an answer you know. Or all they might say is what’s for</p>
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		<p>dinner.. Um hum. Yeah. And so I don't think much changed you know between her and my brothers, because you know all my brothers then got married and they had their wives. And you know how does that expression go? Um, something about a daughter's a daughter all of your days ... or sons... you know.. a son marries and then they go away. So you lose a son when they get married. So that's basically what happened to her and I think she was sort of devastated by that" "There is no filter. And um one of the visits when I was in Parma on a Wednesday. This is when my mom was still living by herself. She made a comment about My Husband and I said mom, why are you still hanging on that?" "And so when this conversation came up, I ended up crying to her... And I said mom, I said don't .. don't you see how well he treats me... what do you still have against him? And she .. she'd give another example of .. and I just I can't believe that you still feel this way. I said he treats me better than dad treated you... I: 45 years later, same kind of story line being played out.. E: Yeah and so you know when I took my mom here to live with us I knew it was going to be difficult, mostly on [my husband]" ERIKA</p> <p>"I don't know... typical I guess mom relationship. I never talked to her in depth about personal stuff." "I think [Kbrother] probably talked to her more in depth on personal matters than I did." "You had to be real quiet not to wake him up and then he always had trouble sleeping and when he would get up he would be cranky. He'd get off work in the morning and work at the machine shop until noon a lot of the times... So then he is really tired and he... I remember so many times as a kid that he couldn't sleep. He would come home all wound up... He was a very stressful kind of a guy...He did have a bout of depression where he was actually hospitalized for like almost a month at St. Vincent Charity." "You know the breadwinner, he's the worker plus he was a big wood worker. Big into wood working so when he was home he could fix anything you know so if something broke he could fix it himself or if he didn't have a part he could make a part. He was just really talented that way. But it was hard for him to try and teach us because communication with him was very difficult." "So like if he ever had a function, he always has Christmas at his house" "Kbrother's always been into cars and can fix anything pretty much. He worked for the metroparks he's retired now. Worked for the parks as a manager of like maintenance crews. Yes he just retired. Yeah in the last six months or so. Yeah, he's four years older." "I don't know she I don't know what you would call it or give it a name. She pretty much a stay at home mom kind of a thing and take care of the kids. She had a few part time jobs but generally she didn't work. She didn't drive generally, she had a couple of part time gigs now and then but she was just a stay at home mom who took care of the kids and took care of the house." "Yeah but he wasn't the type you could sit down and have a long conversation with. No and he didn't like sporting events even. I was always in sports. All of us kids were in sports. He went to very few, he was always working and sleeping" "You know I only... he only beat us a couple of times. I remember one time I road out my bicycle, it was a little tricycle and I road out and almost got hit by a car and got that strap from the barber chair and I remember getting cracked with that thing. He only hit me twice and I remember but umm..." "But it was hard for him to try and teach us because communication with him was very difficult. But we all kind of learned on our own." "Well</p>
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		<p>[Mom] did sometimes to because I remember when we came back from the mall and we were loud or we weren't behaving in the store and she took us in the garage where she had a stick, like a twig, and she would chase me and my brother around the garage saying 'don't you make a noise your dad is sleeping.' You know if we were bad at the store of something. Yeah she'd go in the garage to beat us." PATRICK</p> <p>"and he's, my dad's always been withdrawn from the family cause he worked a lot when I was younger and he wasn't around a lot..." "Which was, it was just strange cause he's a pretty focused guy... Uh-huh, and he was a funeral director for a long time" "And they've never had the greatest of relationships" "I think [Dbrother] just wanted to escape the big family... It can be a little suffocating sometimes" "He is ah, well, he's a good big brother. If I need him for something, needed something or needed help or had a flat tire, I'd just call him. That part is good. I can talk about that part. But as far as personal things, emotional things, he just doesn't, he's just not..." "Umm, a he's not a very nurturing person or emotional. You know he didn't want to talk about feelings..." "It's kind of hard cause we, when we were growing up was when a lot of, it was hard because we were broke a lot, I mean having a big family was just expensive..." "Umm, well, she was tough. My mom's a tough person. And, well, she's not a huggy person.... Well, kind of like, artist tough. Just hard kind of person. Not emotional. I've never seen her cry" "Very, very much task-oriented. So there was a lot of distance between us. It's really been, really recently, maybe the past year, two years, and her and I, our relationship is finally evolving into a friendship" "The way...thru the years we've talked about it and I really think that's a big part of it. It's the emotional withholding. I mean she loved us, I always said, "Well, you know she does, she just doesn't say it all the time."" "Just recently I think it's kind of thawed. So, and I, I think that our relationship has improved because Dad is taken care of." "Umm, I don't think they, well, I can only say that I think the relationships are pretty much the same as they were" "I think I'm still, look I was close to Asister when we were both younger and I still am close to my sister, all my sisters when I was younger and I still am. But I think the difference is that we really didn't hang out much together as we were growing up... Not really, no. We lead different lives." "I don't think we have changed much. I think my, my perception of our various relationships has changed. Because I thought that we would always be close, tight, like be us against the world and that's not how it is and we are... Yeah...like it was us against the world like we would always think alike and be alike and fight the battle and it's not, we were...we kind of fragmented" "yeah, mom ran the house" "A funeral director, well for a long time but he sold his partnership in the business probably twenty-five years ago .. Early retirement. Great benefits. (laughter) And then he, ah, he was a great visionary guy...he had a vending machine company for awhile when I was young.... He owned a Dairy Queen in Bedford for awhile." "Then he ran a trailer park in southern Ohio for awhile" "for 5 or 6 years. He had a pizza business in Ashland for awhile so he kind of dabbled in a lot of things" "I think my mom was, she had a hard time with it cause she was home all the time and my dad, once he stopped...he used to work out a lot, he used to ride his bike around Avon Lake, so he stopped doing that and then, I think, my mom's a doer, go-er, get out of the house kind of person, except my father was</p>
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		<p>never that person” “And my mom, at that point she got more involved with her church and she was out all the time doing church things, doing art things. She had art shows then, so they...he moved in, she moved out. (laughter) So she has a studio in the garage in Avon lake” ““Oh, my role, when my sister left for college, I was the mom’s helper... I was the baby sitter. Oh yeah, I was the one, and I was, I was the mediator to my parents a few times” SHARON</p> <p>“So, let’s see. Jsister, 42. Dbrother is 46. Lsister is 47. Asister is 49. Jbrother is 51. Sharon is however old she told you... Yeah. Uh, then there’s Mbrother who’s 50- Oh, he’s gotta be 55. And, then there’s Cbrother who’s 57. And that leaves Esister who’s 59. You should have 9 in there. 10 with me.” “Well, it’s tricky because there’s 10 of us, and we all have different roles, and we all have different relationships with my parent’s. Some are a little more strained than others. Mine was, I had good relationships with my mom and dad.” “my dad and I had a strong bond. We had a strong connection.. ‘Cause I went to Benedictine.” “No, we had a strong bond until about the middle of 2009..” “Because, we would um, he coached me when I was a kid. He didn’t have time to coach anybody else, because everybody else... There were so many kids ...So, my relationship with him was different than Sharon’s would be, than anybody else’s would be. Because he had time for me. Or, a little more time than he had for any of the other... He may have coached some of the other ones but I get a sense that it wasn’t nearly as enjoyable as my experience was... And, we went to the same High School, so we have a connection there. And, then, I would take him to see football games. High School games. He and I would do, you know we would go wherever they were playing and we’d go see them. So, it was just a nice... He and I would go do these things” “Yeah, Jsister... No, there relationship is not like mine. .. There’s was contentious. .. Theirs is not good.” “I, I don’t think my dad ever really connected with her. And, my mom was more... She lined herself up more with my mom than with my dad.” “So, (mumbled) baseball cards, I have a baseball card collection I still have. He has his cards. Um, we just had things in common” “No, there’s just always, with 10 kids, there’s always different levels of , someone’s not happy, someone’s happy, someone pisses somebody else off, mom’s mad at this person, and dad’s not doing, it just goes round and round, but it’s never something that you know he got shunned into another room or something” “I think about it in my family as there is two generations. There’s the older 5 and the younger 5.” “Yes. West Coast ... Yeah, their life is out there. .. Cbrother does. I would say yeah, one/one and a half years. They get back when they can.” KEVIN</p>
13 Third Generation Connection (grandchildren involvement)	<p>MATTHEW.4.15-4.20; 22.32-22.33; 23.1-23.4</p> <p>ZOEY.33.27-33.28</p> <p>JIM.76.13-76.14</p>	<p>“No. But the grandchildren, when they come to Cleveland, they definitely will see their grandmother, for sure. My niece and two nephews were recently in Cleveland for Thanksgiving and they all visited with their grandmother. She came here for Thanksgiving dinner; And those three grandchildren and their significant others who were here also spent time with my mom), as do my kids, when they’re here.” “Um but she was worried that when she was coming for Thanksgiving that she wasn’t going to recognize her own grandchildren. I don’t know whether she did or not. And we told them, when you see your</p>

	<p>BO.32.12-32.21; 39.2-39.13; 55.11- 55.13; 56.26; 57.1- 57.10; 70.16-70.17</p> <p>STEVIE.11.1-11.2; 11.6-11.7</p> <p>MAC.50.8-50.11</p> <p>ERIKA.13.34; 14.1- 14.2</p> <p>PATRICK.7.4-7.8; 7.18-7.20; 15.9- 15.10; 56.3-56.4</p> <p>SHARON.18.9- 18.13; 38.14-38.15</p> <p>KEVIN.5.7-5.21; 15.4-15.21</p>	<p>grandmother exaggerate “Grandma, it’s so great to see you!! I’m Agrandaughter!” to help her remember. “I’m your granddaughter, Agranddaughter! Grandma, I’m so happy to see you!” And that kind of seemed to work as far as we could tell.” MATTHEW</p> <p>“Yeah. And I mean all of my kids came in for Thanksgiving. And they visited her; we brought her here for Thanksgiving dinner. My kids were fabulous” ZOIE</p> <p>“I have actually what has emerged in the last year is my nephew, ‘Uncle Jim when are you coming down let’s do some jamming?’” “Yeah, well he plays trumpet.” JIM</p> <p>“and I’ll stop by and see them or call them because my nephew is there and he’s ... Yeah so I try and give him whatever I can and he is sometimes I’ll say I’m coming over and I’m having dinner or lunch with grandpa do you want to come? He’ll say I’ll come anything to get away from my parents” “[My daughter] is the assistant dean of the admissions and financial aid at the Penn State School of Law at the Dickenson... So they brought her because of her activism and her social, talk about white bread, she went to law school there. “ “Yeah [financial responsibility of father] was sort of delegated to [Jim] but as yeah it’s his baby. So long as he doesn’t die before my father it’s good. We laugh about it quite a bit but my daughter didn’t think it was very funny...(Laughter) Its like you’re the attorney or whatever.” “And [Rbrother’s] wife had to go over and get the stuff out of the house along with their son... who... Jim’s like I don’t know if a 17 year old should be seeing all this and I said yeah he’s only seeing part of what’s going on. He is not seeing the whole picture of this man’s life, he’s just seeing these weird little intervention things not the full loving... you know what I’m saying, experience.. A 17-year-old kid.. Of his grandfather... Yeah so there is all that kind of dynamic” “Yeah my daughter was in town to see dad on break over my birthday. So we hung out in Springfield for a couple of days and had a big dinner” BO</p> <p>“Yes and all those little incidents kind of led to you know few and far between and then more and more and even the girls would notice, my kids” “So it was ‘Mamita mamita you asked us that again.’ They would do it in kind of a light way” STEVIE</p> <p>“My wife was down in her office and then the kids would be in school. But she caught the kids also during summer. Who did I have then? I had the three kids already. I had the youngest and then the two in high school. Sometimes I would have people come home to visit.” MAC</p> <p>“my niece was talking to her on the phone and ... long distance and my mother’s speech was slurred. And she called her dad, Patrick, and said there’s something wrong with grandma.” ERIKA</p> <p>“And I think the first weekend we took her was... it coincided with a baby shower for Erika’s daughter-H</p>
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		<p>I think... I think that was the first weekend it just... Yeah it's just like let's just take her and get her out of your hair for the weekend. It was one of the first weekends." "Sometimes she would get mixed up with Kbrother or Gbrother but she would know our kids names" "So it's awkward when Erika like, where was it... they had a pre-Christmas thing at Erika's Daughter-E's house, which is Erika's ... She had a holiday thing and everybody was going to be out of town so she had a holiday thing" . "Our photo album she doesn't remember we got married. Unless I tell her who my daughter is she doesn't know." PATRICK</p> <p>"He was (laughter) So, you know, he, and I know my sister Lsister goes and she brings her daughter, Bella. He doesn't know Bella... Yes. Oh yeah, all the grandkids, he would play with them, have fun with them, all that stuff so" "That's very telling because like my father's very affectionate, has always been affectionate with the grandkids." SHARON</p> <p>"well my mom told me that she went and saw him Sunday, and he asked how tall was Pson. Cause... Yeah, something, something, I don't know, maybe something my mom had said triggered it? I'm not really sure... Uh, not, not so much. Just like any other grand... they're not close. They're as close you could be. They don't have a real tight connection" "I: You come home drained. And, how does Pson feel about that? Does he go out there with you?... K: Yeah. Whenever I can I take him out there... He, uh, he's a typical 16 year old. You know, he sees it. But it's not me. It's his grandpa. You know he's never really had... because my dad was... well, when Pson was born, my dad was already old, a senior citizen at that point, so there was never really a chance to go do stuff with him. So, the bond isn't real strong. I mean, it's his grandfather. But, they never really had any... grandson/grandfather time. That didn't happen. So, the connection, it's there, but it's not as hard on him ..." "um. I don't know how it was with my dad. Because, at that point my dad was not home very much. Cause he was working odd jobs, and this and that and whatever. Um, I don't know." KEVIN</p>
14 Contract Between the Generations/Intergenerational Themes (Mesosystem and Exosystem)	<p>MATTHEW.22.27-22.33; 23.21-23.31; 24.5-24.10</p> <p>ZOEY.24.18, 24.21-24.23, 24.27-24.28; 29.13-29.18</p> <p>JIM.65.20-65.21; 66.1-66.18</p> <p>BO.10.18, 10.22-10.23; 11.1; 64.16-</p>	<p>"... So she can't remember them, and therefore she thinks that they can't remember her. You know, the principle of reciprocity. She's worried that they have forgotten her. And I try to reassure her that they have not forgotten her at all. .. Um but she was worried that when she was coming for Thanksgiving that she wasn't going to recognize her own grandchildren." "And I've made plain to my children in .. what I am asking of them when I am older... I asked them to be as kind to me as we were to their childhood pets. ..You have not only my permission to do that, I'm asking you to do it" "I said, ... Don't do me any favors. If you want to keep me alive. You go right ahead. If there's no point in keeping me alive anymore, pull the plug, please, I won't care." MATTHEW</p> <p>"- I cared for my mom to honor my dad." "And I said, "I am doing this because it is what dad would expect." "- the last year was terrible for me because oh god on so many levels if I ever had a fantasy that me and mom would be able to reach a resolution in our relationship. And anger at having to care for her</p>

	<p>64.1873.4-73.6</p> <p>STEVIE.20.20-20.24; 35.5-35.7; 35.26-35.29; 37.29-37.31</p> <p>MAC.43.12-43.14; 60.26-60.28</p> <p>ERIKA.53.14-53.27</p> <p>PATRICK.42.1-42.26; 43.2--43.25; 44.10-44.16</p> <p>SHARON.13.4-13.5; 15.13-15.18; 31.6-31.13; 53.4-53.27; 76.3-76.6</p> <p>KEVIN.</p>	<p>when she never cared for me. And guilt that I could care for my father – and I mean physically care for my father, lovingly – and that I could, I had to make myself... It was an obligation. Right. And that felt really crappy” ZOEY</p> <p>“it’s a privilege like I said. I am very privileged to be able to do it. Uh, we’re all okay with it; it just seems like this is what we do at this point in our lives.” “Right, in sociology there is a concept, its called a contract between generations... And that is what that is, it’s a contract between generations. Its like when you’re little and need care we give you care and you give me care... Right and its sort of determined by the quality of the relationship or your sense of obligation... Filial obligation... yeah so it just seemed like it was time and also it was somewhat modeled on my parents taking care of my grandparents.” JIM</p> <p>“My dad fits into it because he’s my father and...” “so how he fits into it is that I can for him, I love him very much, he is a sweet man, and given the... opportunity to be here like I mentioned it was a no brainer.” “But with this there is the whole family watching and I don’t want to let Jim or my father down. I mean it is important to do it is just one of those things that is important” “That [Dad] be comfortable and be happy in his old age and that he is taken care of... And that is pretty much it that he is looked after.” BO</p> <p>“In fact if there is ever a potential conflict it is our closeness verses the sisters of my mom. Sometimes they try to take to matters in their own hands where as like okay we have to get our act together because auntie is, they have a strong personality so they have a way of like this is our sister but this is our mom” “my brother’s taking care of my mom now but he has a wife who’s really nice but if usually it’s the daughter. Usually your mom stays with the daughter.” “It is also a big burden to take in even if it is in our culture to take in your elderly. Here in the States you put them in homes but back home we take them in and its not always easy so” “It is just cultural that we always take in our elders so so far” “It is just cultural that we always take in our elders so so far I mean my husband is just what you see is what you get if he’s just a little like not chipper he shows it but it is not personal” STEVIE</p> <p>“I think in many ways it impacted her in a good way. She’s a very good example like my parents they are a very good example about you know about marriage and sticking together and taking care of people” “I mean we are taking steps now towards what the final care would be. I am sure that is going to change over time depending on what my mom needs.” MAC</p> <p>“And you know at the point we are in our lives. And I know a lot of people do this. And in the Asian culture, it’s just what you do... You take care of your elders... And I feel guilty that I couldn’t hang in there and do it the whole way. Um and fortunately my mother has savings and investments that my dad was sharp enough to look into... She couldn’t afford to be there.. But that’s there we are now and so</p>
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		<p>having her there, I mean I can just .. it's still new for me" ERIKA</p> <p>"I've even suggested to Gbrother, we thought that my sister should have been getting compensated from the estate. She should have been but she wasn't and I kind of thought after we met with these lawyers she was being compensated. Some stipend of some kind and then we find out that she wasn't getting anything other than a little assistance with food. Groceries... I think they put air condition in her house things out of my mom's estate, which is obviously fine." "You know and its I brought it up you know but I think when it is all said and done I think when my mom is gone and we settle the estate I think my sister should get compensated..She gave up three years of her life." "... this is kind of funny, not funny but when my father got in a big fight with his siblings because his my aunt, Aunt D took care of her mother took her in. for I don't know I forget how long I was younger then so when the estate went to get settled she thought she should get more and my father was like 'no we are splitting equally.' That caused a big divide and they didn't speak for hardly ever after that which." PATRICK</p> <p>"he can't take care of her, she can't take care of him, we have to do something..." "Well, they thought that maybe they could take him in to their house.....and take care of him but really we all kaboshed that because its, we just couldn't, I just couldn't see them doing it... It's a lot of work" "...when we first started having these conversations. Oh my God, Dad has alzheimers. What do we do? What does it mean? Does that mean they'll lose the house? Where's mom going to go? Where's Dad going to go... And we didn't know what to do. Who's in charge? Who's going to do this? What if they need money? Can we do that? It really was this very, so up in the air, and so vague and so just almost unspeakable. Different scenarios of how bad it could be and then as we got thru the process each of us kind of found our way, our own way of how we could cope and then it kind of fit together" "I guess I kind of expected my sister to say, "Yes, I'm moving home." The one in Canada. "This is a big deal and I want to be there for the family." Like my brothers would say, "Yes, I'm taking a leave of absence from work, coming into town and we're going to figure this out together." But in the past, I think that's what they would have done. In my brain. But now, no, they didn't do that and I'm kind of like, "why not?" "This is a big deal and we're doing this together." But they didn't see it that way and I was a real, kind of a...it was kind of crushing... You're telling me that this is not that important?... yeah. I know, this is important. That was a real change cause when we were kids, even when we were, even five years ago, they would have said...I think even in my head, they would have come." "Well, umm, we touched on it a little bit. There's a practical side of it that if my father passes away what happens to Mom. She can get in and out so she's able to stay in the house and (something garbled) It's a huge concern, how she'd be taken care of so what happens when he passes on, what happens to her? So that, we've had that conversation." SHARON</p>
15 Support in Sibling System	MATTHEW.13.2 3-13.24; 16.20- 16.25; 18.20-18.22;	"one of the forms of support that my sister and I have been able to offer to one another, and we do have somebody that we can talk about this with and not worry about the social taboos or whatever.. but we at least can talk honestly and openly, and we don't always agree." "The relationship has always been there

19.26-19.27; 21.5-21.6	all along, and it's available to each of us. Dealing with our mom's, as you say, cognitive decline. You know that's just the latest chapter in something else we're both sharing." "Um I think it has to do with two things. One is the emotional support that has to with navigating the relationship with our mom, who's a piece of work – there's no doubt about it" "But my sister would later say, "Can you believe what mom said about you!" You know, and that's support. At least somebody else [laughing] somebody else recognized it too!" MATTHEW
ZOEY.29.4-29.5; 36.10; 38.10; 42.10; 43.20-43.21	
JIM.69.7-69.8; 84.6; 62.22-62.25; 59.16-59.26; 67.21=67.22; 63.16-63.17	"One of the things that serves us well, my brother and I, is that we actually talk to each other. And so we hastled" "If my brother weren't here, I don't know what I would do" "I mean there's a level of connection that for me has been there my whole life." "yeah, I have absolute confidence that we would be able to talk out almost everything." "The world of feelings. I have really helped him, over the years, in some dimension of interpersonal relations because he didn't get the affective part. They were mysterious to him. And he does listen to me. And I think that – we'll see what he says – but I think that he feels loved, and supported, and not alone" ZOEY
BO.55.6-55.9; 63.11-63.21; 65.3-65.8; 72.16-72.21	
STEVIE.14.13-14.14; 29.24-29.25; 30.1-30.8; 30.22-30.26	"Yeah because you know cause we all love our father and we are interested in his wellbeing" "We are trying to be umm proactive trying to take care of him." "Oh, we're very connected.. We're very connected like I said we talk several times a week, we're on the same page with Father, we're on the same pages with RBrother " "Well he [Rbrother] supports what I'm doing... He supports my role... And I mean the other thing I do is, is like there's just trans-, I'm a big believer in transparency especially if I am in the financial stuff. I said this is this month and here he gets statements, I say this is where we are you know so that everything I do is transparent. Nothing is mysterious but..." "I get I get umm they they both tell me, well Bo especially tells me that I am doing a really good job." "Basically we share a really strong interest in being helpful to dad like we'll go to Springfield and ask him to reminisce about stuff" JIM
MAC.54.16-54.19; 69.5-69.12	
ERIKA. 11.8 - 11.9; 19.13 -19.14; 70. 1 - 70.18 ; 41.2-41.8; 28.27-28.31; 29.2-29.3	"So Jim and I talk regularly pretty much and he appreciates to at least to have me to bounce ideas off or at least to vent but I mean we can talk, we have the same concerns and he's sort of more in it because he's viewing the financial, he's got his hands in the financial stuff" "So I told Jim I would just print the envelops up so when I came back from Rhode Island last time I'll have a stack of envelops for a couple of years for each of these addresses ... Well yeah that's the idea. I don't know what I mean that is sort of my understanding of what we're supposed to be doing as a family...In supporting each other and that's why Jim was so bonkers when he got no response from RBrother. Its like what the hell do I have to come down there and do it myself and then on top of that I don't want to be the asshole here which is like you know" "Its not, I'm doing it because it is important what we're doing and it's a delegation of responsibilities. One person should not have to do everything and yeah so I support Jim emotionally, we throw ideas back and forth on how things should be handled. RBrother does that to to some degree usually a lot more reactionary and more from the scare tactic side of things instead of holistically how
PATRICK. 3.26 - 3.29; 20.21 -20.23; 21.5 -21.22; 2.17 - 2.22; 3.1; 4.7 - 4.14; 5.20-5.24	
SHARON.30.17-30.20; 31.12-31.13; 74.3	
KEVIN.14.2-14.6;	

	15.27; 35.10-35.12; 37.22-37.26	<p>things should be” “I mean there is some hanging out and as brothers we can hang out and laugh. I mean that has happened but the foci has been mostly concerning dad ... I mean we have good times together doing stuff like that but there is a particular focus” BO</p> <p>“we said okay we are self medicating why don’t we try to educate ourselves and talk to professionals.” “Yes but we’re still thinking she already needs a companion. Other things we are trying to set up as siblings is, you’ve heard of caring bridge website?” “Yeah I think it was excellent, it was like, it is excellent because we all live in different places and to streamline communication so you don’t have to repeat yourself. What is the latest update on my mom and to get my aunties involved and just to have everybody on the same page. Even though she doesn’t have cancer, she’s got a condition... Caring bridge helps to stream line the communication update those that are like ‘what’s going on?’” “So we have some of these projects: the seven-day sibling thing, the caring bridge thing, streamline communication.. Yeah, the weekly Skype meetings, so far that is what we have. When she travels she needs a companion umm other things...” STEVIE</p> <p>“We contribute to each other like if my eldest brother needed some help cause he’s had kids he’s had some problems with his kids” “He got divorced uh and so sometimes I would help him financially” “I think regularly with technology almost everyday we are talking about what is going on... Wife-emotional support uh siblings also ... Yeah, organizational support from the siblings” MAC</p> <p>"Yeah, so... I mean GBrother and I flew out there. And we had to fly my mother home. And you know had the funeral..."Yeah. It was very interesting. So I probably ... you know as close as you could be to siblings you know we all had really good relationships but when it came to the care of my mom, it got interesting." R: "So they're like events. Like big events that are important to people. People come together" E: "You know with brothers, I don't know. It's just .." R: "Not relationship. It's not ever been really like that." E: "No." "Um but if I have something, you know, crucial to ask them or tell them, it goes to all three. You know... Yeah, yeah.. so yeah you know, we talk about changes. You know GBrother noticed one of her legs swollen after she had been in the wheelchair for a while... And so I didn't .. I didn't notice it but GBrother did. So you know we had the nurse look at it. So things like that. So we .. you know we talk and we share what we see" ERIKA</p> <p>"god bless her for doing that you know. She did it in, it obviously talking to her I was never in that role where she lived with us ever. I mean since years and years obviously so Erika took that on and got to see day to day what that was like." "There was very the big brother so I always respected my big brother and big sister" "Erika has always been there as a big sister. ...so Erika has always been there for me." "We tried to restrict her to the microwave. We had meals on wheels come in there for a while so we tried all different things. I remember the microwave she actually had trouble working the microwave, like come</p>
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		<p>on put a big piece of tape and I go mom all you have to do is hit this one time for 1 minute or twice for 2 minutes you know simple and she couldn't figure that out." "you know somebody had to go over there and help clean and we took her shopping and doctor appointment. We would take turns doing that and it just got steadily more problematic with her issues, you know?" "So we all agreed that on Saturdays we would take turns and came up with a schedule and then Gbrother took over. He made the schedule and we would take turns picking her up so my sister would get like a day off. Every Saturday just for the day. That is how is started and umm... that was helping her out, she really appreciated it." "Yeah we started taking her on weekends because when this came to a head we saw that she needed help so we were the first ones to say, okay I'm going to pick her up on Friday night and bring her back Sunday." "Well I mean she lived by herself. We would go over there and cut the grass. We would take care of maintenance issues." "But umm... so yeah we used to go over there taking turns." PATRICK</p> <p>"But [KEVIN] is, he is connected. He does call my mom and see how she's doing. He does call me. He asks me how Dad's doing. "Do you need me to come out? Is everything okay? Do you need anything?" I can call him and talk to him about it" "then as we got thru the process each of us kind of found our way, our own way of how we could cope and then it kind of fit together" "Um, mostly, listening support [from sibs]." SHARON</p> <p>"I mean it's good that we have lots of brothers and sisters, but it's good and bad because we each try to do whatever we can but we never know what the other person is doing so all of us know a little bit, but none of us know everything. And, time is short during the day it's hard to communicate with everybody because there's just so many of us." "Sharon has a good... she, she works the hardest at maintaining the connection" "and you accept it. I mean that why I don't have any issues with my brothers or sisters. I just accept them for who they are and I just hope that when things get rough that people step up as much as they can" "I think its indecisiveness. Yeah. I mean her and I aren't super close, but I'm happy to see her. Whenever we are together we chat for a little bit. So, I am at a point where I'm not really disagreeing with any of my brothers.... I'm just happy to have them... with my crazy life the way it is and the experiences that I've had. It's like hey you know we're all in this together so do whatever you can." KEVIN</p>
16 Wide Reaching Support Network	<p>MATTHEW.2.28-2.29; 3.1-3.7; 3.11</p> <p>ZOEY.5.6-5.27</p> <p>JIM.24.5-24.6; 48.11-48.17; 49.7-49.8; 50.8-50.10; 52.17-52.21</p>	<p>"Uh, an aunt, an uncle (my mother's sister and brother), their involved." "And one of their children, first cousin is here. And I have long distance relationship with my own two children. Obviously they're involved with my life but not on a face-to-face basis. And to a lesser extent, my nephews – my sister's three children – also family members who are a part of my life," MATTHEW</p> <p>"I talked with a social worker with the Alzheimer's Association, and a couple of people whose parents had Alzheimer's... And I have a very close group of friends in Cleveland who have been wonderful supports.... Friend #1. When I couldn't – when I was in the hospital for a number of months – she</p>

	<p>BO.1.5-1.18; 15.20-15.24</p> <p>STEVIE.4.10-4.13; 10.20-10.27; 23.4-23.6; 37.16-37.18; 13.8-13.11; 20.20=20.24</p> <p>MAC.19.11-19.12; 22.17-22.18; 22.24-22.25; 50.18-50.27; 51.1-51.9</p> <p>ERIKA.3.1-3.9; 8.9-8.10; 8.22-8.24; 42.21-42.22; 46.9-46.10; 46.26-46.29; 17.30-17.32; 18.4-18.5; 31.28-31.33</p> <p>PATRICK. 4.6 -4.7; 4.19; 5.3 -5.13; 6.22 -6.26; 7.17 -7.18; 15.9 -15.13; 22.1 -22.14; 29.1 -29.3</p> <p>SHARON.4.19-4.20; 88.5-88.9</p> <p>KEVIN.17.21-17.23; 23.1-23.5</p>	<p>[Fraggle whimpers] she visited my mom, who was at home at the time. She took her to her doctor's appointments, and just, you know... Another friend, Friend #2, made sure that if she had any needs... I mean my friends stepped in... And my [Fraggle whimpers] sister-in-law, my ex sister-in-law, flew in from Boston for a couple of weeks to assist my mom" ZOEY</p> <p>"and my sister-in-law, my sister-in-law is actually the train for that particular engine... RBrother's spouse... Yeah so she's more likely to follow through" "I: But there's still this connection maintained, umm... who are the other people that might be, the people who are involved with the support in this or like the caregiving at least? [Rbrothers' wife] is yeah in terms of yeah I mean [my - Jim's wife] basically gives me permission to go down and hang out with him." "Uh, so and umm... Lisa [researcher changed name for research purposes of confidentiality] has a good relationship with my dad too. My, Bo's wife, yeah." "I think that, I think that he is really happy with all of his uhh... all of his children's wives because everybody has everybody is really affectionate to him and very caring for him." "Well, before he came back [Rbrother's wife] and I went to a couple of places in Springfield... Yeah she was very helpful with that also... And we looked at them together." JIM</p> <p>"Yeah that's right. Yeah no I did, he's close geographically and I feel it is important that I spend time with him especially at this point in his life and that's also one of the reasons I sort of came back here because you know he's not going to be around forever. I'm an hour away, its not that big of a deal my father's here, my wife's parents are still living, he's still living so I think it is a good mix". I: And do you get to see actually your in-laws while you are here in Richmond ? B: I can but their family is on a different community, they're in a different plan than my dad like over our dinner table everything was discussed. I don't know what was discussed at their dinner table... Well you know its like the closed up version versus the open just put it all out there and so it's a different thing so" "That my brother RBrother's wife and Jim pretty much did the walk thru and looked at a couple of places and this was, they felt was the best place for him in Springfield. It is a good place. They do provide very decent services. For what it is it is perfect for him though I wish he gotten a two bedroom there instead of a one bedroom" BO</p> <p>"My kids, my husband who is a physician. Yeah he is there to support and he also is close to my mom so he gives his opinion. Who else? We have an extended family like a little clan umm there are about four other little Pilipino families in the Avon area " "Then my husband would say, 'mom why don't you start doing puzzles or crossword puzzles, Sudoku stuff like that?' ... You could tell at one point. She listens to my husband too so when my husband said, 'hey mom you asked me that' clearly you are getting older we need to work harder. You could tell that she got alarmed, the next hour she was trying to do crossword puzzles" "She doesn't tell us, she never used to tell us she is depressed she would call her sisters and say 'I'm depressed' and then my auntie would say 'you know your mom is depressed.'" "Yeah just the seven</p>
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		<p>siblings in fact the spouses don't even get on it. it is just the seven siblings but if they wanted to they could but they let us handle it and they get updated after the call" "my aunties, her sisters whom she is very close to ... Yeah and she is very close to them" "In fact if there is ever a potential conflict it is our closeness verses the sisters of my mom. Sometimes they try to take to matters in their own hands where as like okay we have to get our act together because auntie is, they have a strong personality so they have a way of like this is our sister but this is our mom" STEVIE</p> <p>"Right and the household is got two dogs, a bird, and a fish. They all have our last names." "So when she's here even my wife loves her." "Right you would know and my wife appreciated that you know and she loved it. She learned a lot of recipes from her. They cook together" "Well in the Philippines she has her sisters there.. Well in the Philippines she has her sisters there...No she lives in the Philippines. One in the US lives in San Francisco. She has her own dynamics there hardly but they're still close. When my mom used to visit in Vancouver they would get together. She is in Seattle not San Francisco" "So they would see each other and sometimes she would fly out to LA and her sister would meet her there. So they are very close, close Stevie could tell you more about that to a fault sometimes Pitting... pitting I want to be careful what I say... they gang up on us kids.... Yeah just pick up my mom and bring her to a friend doctor and we wouldn't even know what's going on. So I said 'hey guys don't get mad about that because that could be a big help because if we are all busy her older sister. They love her too so lets...' "MAC</p> <p>"So we had her birthday party December 4th. Her 90th birthday... Yeah and so my brothers came and their wives and one of my daughters, two of my daughters came, and some nieces and nephews and she was in this room with all of us but she did not hear any of the conversation across the room." "Okay so now, of course, my husband My Husband that you met. Um I have three daughters. The oldest is 35. The middle daughter is 30. And my youngest is 27." "And then I have my three brothers. GBrother, KBrother and Patrick. GBrother is the oldest. KBrother is four years younger than I am. And then Patrick is the youngest. Four years younger than KBrother. Patrick is the youngest." "For me. And you now my co-worker at work said. She said this to me. Well it's because he loves you. That's how much he loves you. He's willing to put up with her." "And LDaughter said to me, during this meeting. Mom, she said, meeting your kids on a Friday night for a fish fry should not be that big of a deal." "My initial feeling after this meeting with the girls was, I can't do this. But when I came home that night, I wrote and email to my three brothers. And I said today my three daughters lovingly told me that grandma cannot live here anymore. And I said they know better than I do. And they can see the reasons. And so I want the three of you to figure it out. And just let me know what you come up with" "So what started to happen... and for the first year um you know I had very little help. Um and my one sister-in-law, GBrother's wife, maybe it was a Thanksgiving Dinner because we were all here. My mom, of course, was here. Gwife kind of called us all in the den and she basically said to her husband" "She said to her</p>
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		<p>husband and KBrother and Patrick. You three need to help out here and you need to come every Saturday and take her and give Erika a break” “Because who was the person that said bring her here? I didn’t have ... I couldn’t ask My Husband. Because she treated him so badly for 30 some years but when he saw what I was going through. Back and forth. Back and forth. Back and forth. He said you just need to bring her here” ERIKA</p> <p>"So as we started to learn, my wife was integral in this talking to Erika here and there about... well my sister wanted a break periodically." "Erika probably has the email I don’t think I could find it, but you know Erika started venting and she talked to My Wife a lot." "my wife had a lot in doing this and telling her, you know you need to ask for more help and demand more help from the rest of us. Right, my wife kept putting it in her ear you know you need to put it out there that you need help. So she put this email out to everybody that...Partly I think My Wife helped give her the courage to send it but Erika goes this is becoming very burdensome for us and if things don’t change, something like you know I’ll drop her off at your house for three months and you will have her" "You know my wife helped out a lot doing the bathroom part and helping her dress, things like that because its awkward still with your mom you know when you get into the..." "I... she just... I don’t know the exact wording but she just let it out there and which obviously made the situation even more uncomfortable for everybody....But I... Erika’s Husband put up with a lot and he’s by letting... its not like it is his mother it is his mother-in-law that he let come into his house for...It is my sister’s house too but and plus because of the outward negative commentary that he would get with that I put him up on a pedestal." "Lack of..My wife has done more for my mom than Gwife and Kwife have ever done for my mom." PATRICK</p> <p>“she settled on Avon Oaks because it was recommended from a friend of hers...” “No. no other sibling. I mean no other family, no other person that has this. I’ve talked to elderly people. At work, I word with a lot of elderly volunteers. So, they have, one of my coworkers had a mother... her mother had alzheimers. She died of complications from Alzheimers. SO, I’ve talked to her, but I haven’t talked to anybody my age who has a parent who’s going through this. And, I’m really anxious to talk to somebody.” SHARON</p> <p>“So, yeah, you would think the people closer would be more connected to the ones on the west coast... Cbrother and Asister, they make a much better effort than some of the local people at staying in touch.” “but [Jbrother’s wife] was very much against the nursing home. So, I think that may have influenced his thoughts on how it all works. That may have softened since now my dad’s in the system and Jbrother sees what it’s like. Um, they do come to visit though. They don’t stay away. I mean they came and they helped... they put pictures on his wall. They tried to make it comfortable for him.” KEVIN</p>
Cultural Guides (Macrosystems) (External External)		
17 Religion and	MATTHEW.2.12-2.17; 7.21-7.25	“I’m very active with the Cleveland Jewish Motorcycle Club, which is somewhat of an oxymoron. There are a lot of Jewish motorcyclists, believe it or not. Um I was the founder of the Cincinnati, Ohio Jewish

Ethnicity as Guide to Culture (Macrosystem)	<p>ZOEY.40.24-40.30</p> <p>JIM.42.24; 44.2; 44.9-44.17; 45.1-45.3</p> <p>BO.1.17-1.20; 27.2-27.11; 28.2-28.6</p> <p>STEVIE.20.29-20.31; 21.1-21.6; 21.14-21.17; 21.19-21.20; 37.29-37.31</p> <p>MAC.10.11-10.13; 11.10-11.22; 12.11-12.12; 41.9-41.10; 50.18; 50.22-50.27; 51.13-51.14; 52.4-52.6; 54.5-54.6; 39.12-39.15</p> <p>ERIKA.53.14-53.19; 28.27-28.31; 29.2-29.3</p> <p>PATRICK.15.9-15.13</p> <p>SHARON.17.24-17.26; 49.8-49.12</p> <p>KEVIN.12.13-12.14; 27.24-27.26</p>	<p>motorcycle club a few years back and when I moved to Cleveland I got connected to the Cleveland Jewish motorcycle club, I got very involved with that group. So that's another hobby." "I founded the Cincinnati Jewish Motorcycle Club as a way to meet people. I knew I liked motorcycling and I like motorcyclists. So I said – and I worked at a synagogue and I was around Jewish people, so I said, maybe I can combine all those things and meet people. Which actually did happen." MATTHEW</p> <p>"You know what a Shive is? The Jewish morning ritual? Well, it is 7 days when the family receives guests. It's called Shive because in Hebrew, shive is seven. Um, he recently went to the funeral of a man that he was quite close with. but he didn't know anybody else in the family. Now you would have had to drug me to get me to go. And he not only went, but he was among the last to leave that evening. And I said to him, "what were you talking about?" and he said, "Oh I met Marilyn who did this, and I met... and I thought you're a crazy person." And he's like "flat out crazy person." He's curious. He likes people." ZOEY</p> <p>"I went to boarding school." "the schools in Springfield were awful" "but what I do remember is at this, this will totally blow your mind. They would have bible study in the fucking public school. Exactly... In Springfield they would have, someone would come in and talk about bible stuff and and because I'm Jewish they would, I would go out with the teacher and we would go sit somewhere and draw pictures or read something or do something..." "So I was in fourth third or fourth grade so I was uhh... 8 or 9 years old it was 55 something like that. Yeah so that was part of it, the schools were not that good and then..." JIM</p> <p>"I: That's great! Does he practice Judaism still ? He umm no but he is very aware of it. He is shockingly so because most of the people of his generation their parents or their grandparents were Orthodox, there wasn't such a distinction so there is this whole sort of generational thing. So he knows things that flip me out from an Orthodox perspective." And he just was really cantankerous and really just holding that grudge tightly you know. It must have really hurt him badly" "But it is interesting so I asked [Rbrother] for forgiveness for about three years in a row and then I, there is this old Jewish the thing is you can only ask somebody so many times and if you ask them directly and they don't forgive you, you only have to do it twice really umm... and I mean according to Jewish law I believe two or three times and if they don't forgive you than it is their problem basically." BO</p> <p>"Including my mom they were five sisters. My mom is the second among five sisters just to give you an idea of how they grew up. They grew up with a closely nit conservative Pilipino Spanish family" "Yeah so my grandfather and my grandmother were very conservative. They were strongly Catholic they would go to mass all the five sisters together" "Right and my grandmother was into Spanish theaters. So they grew up in this, you would say, upper middle class family... were in the good families... they were</p>
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		<p>sought after. My grandfather wanted all of them to become nuns you know that type.” “In the Philippines because the Spanish were there for 300 years so my grandfather is actually not half maybe a third” “It is just cultural that we always take in our elders so so far” “”Very Catholic very Novena oriented you know pray the rosary everything is proper. It is like Victorian just like Downton Abbey” “It is just cultural that we always take in our elders so so far I mean my husband is just what you see is what you get if he’s just a little like not chipper he shows it but it is not personal” STEVIE</p> <p>“Okay well the culture here is... well let me talk about the culture there. Third world country we grew up seven children in a household. We were spoiled because its not uncommon for a family like us to hire another family to live with us... In most cases it is just what we call yayas, which are nannies... So it makes it easier for the wife or the mother because there is somebody who cooks and washes the clothes and gets the kids up for breakfast ...It the culture like umm it is a very paternal society like the dad is this” “Umm... in that culture in the hierarchy yeah they are always up there and then there is us and then there is our help, who we take care of very well who we love. Then sometimes (mumble) but that’s the culture and so coming from there. Coming to the US you appreciate... owning your own home, doing your own laundry, cooking you know. I mean you have kids you got to take care of your kids. There is daycare. There is all this, it’s a... how do I say this? You’re always moving, you always... well over here you are more independent.” “Very family oriented. In a way it is very good. When one is in trouble whatever it is financially or someone failed the grade or you know had to repeat a year it is always like” “Okay and opportunity also, umm and whatever problems we have they are our own problems. If I have financial problem I can solve it here without having to consult ... Unlike there everybody knows in a way, ‘here’s something to help you out’ in a way it’s nice but then you become kind of dependent” “The culture of my mom and her sisters like to cover up things see.” “Well in the Philippines she has her sisters there” “She has five sisters. One lives in the United States, four that are there. She is closest to her eldest sister ...No she lives in the Philippines. One in the US lives in San Francisco. She has her own dynamics there hardly but they’re still close. When my mom used to visit in Vancouver they would get together. She is in Seattle not San Francisco” “Yeah the Philippines is very well the main city is very small. Generations, three generations could live in the same area four generations. It’s not like the United States where are state to a different state here.” “Really mixed already. We’re all mixed. I mean 500 years of Spanish rule and then there was Portuguese and then there was the Japanese and then the United States and the United States gave us our independence. We became the Philippines.” “I was going to say we were a very close family almost like an ideal family in the Philippines. Some called us compared us to the Sound of Music family.” “My dad was very religious in his final years. My mom was always religious... We were raised Catholic” MAC</p> <p>“And you know at the point we are in our lives. And I know a lot of people do this. And in the Asian culture, it’s just what you do.. You take care of your elders.. And I feel guilty that I couldn’t hang in there</p>
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		<p>and do it the whole way” “And the other thing was my parents had this... because I was the only girl you know. They had this vision that the person I would marry would be from Parma. He would be Polish. They would know his family... It would be just the perfect picture. So he’s from out-of-town. His parents are divorced. I mean he is Catholic though but that wasn’t enough. That didn’t weigh anything.” “No, no. The only little thing was that he went to church. But so this was the first time in life that I had some conflict with my parents” ERIKA</p> <p>“So it’s awkward when Erika like, where was it... they had a pre-Christmas thing at Erika’s Daughter-E’s house, which is Erika’s... She had a holiday thing and everybody was going to be out of town so she had a holiday thing” PATRICK</p> <p>“Could be part of it. Because he’s a pretty proud Slovak man... and he’s still protecting his space. Protecting his stuff.” “S: No. No, I think that we, we were with each other, we kind of were, but we didn’t really learn from our parents.... They were hard-core Slovaks, get the job done and then as we got our own space and stuff, and then we were like “okay, I love you, man. Give me a hug” SHARON</p> <p>“Yeah. Catholic. You marry for life, and for good or for bad, for better or for worse. And, I think with 10 kids there was a lot of worse and not a whole lot of good” “You know, and my mom, was typical old school Catholic trying to keep everybody in line. Um, it wasn’t like it was with my sisters. Where it was difficult for them because they had a hard relationship with my mom and my dad was not really there” KEVIN</p>
18 Different Time (Generational) – relationship with parents (Macrosystem)	<p>MATTHEW.17.4-17.10; 26.4-26.14, 26.19-26.28</p> <p>ZOEY.25.11-25.13; 25.16; 25.18-25.19</p> <p>JIM.29.1-29.22; 41.15-41.18; 42.10-42.12, 42.21-42.22; 45.1-45.3; 33.21-33.29</p> <p>BO.18.1-18.13; 19.18-19.24; 43.19-43.20; 49.22-49.24; 50.5, 50.19-50.21</p>	<p>“I think of in hindsight, as a typical, middle class, suburban American family, you know, a mother, a father, a boy, and a girl, and a dog, and a station wagon in the drive way and that sort of thing... We did not have a picket fence, but we had an apple tree in the backyard, with a barbecue. It was somewhat idyllic to my looking back...” “Um I was the first child...And at a very early age, we’re talking like toddlerhood, maybe even prior to that, except, I have no memory of it, I understood, on a totally nonverbal level [Fraggle whines beside Matthew, trying to get his attention], that I was on my own. And I would have to take care of myself emotionally and otherwise. [Fraggle still whining beside Matthew]. And the corollary of that was that not only was I going to have to take care of myself, I had to take care of my parents, emotionally. And how that message was communicated, I’m not exactly sure.” “She was given that same message, I believe, in some way. Except, she didn’t go along with the program. She was the “emotional one!” See, I was living life up here [pointing to his head]. She was in the gut. Totally. Her nickname, when we were kids, from my parents, lovingly – do you know the actress, Sarah Bernhardt? Alright, she was a famous actress of stage. Like a big emotive actress in the ‘20’s and ‘30’s. For my parents, growing up in those years, Sarah Bernhardt was like Meryl Streep. She was the actress, the iconic actress, always emoting, you know on stage, maybe in some silent films. So my sister’s nickname from my parents when growing up was, instead of Sarah Bernhardt, she was know as Sarah Heartburn”</p>

	<p>STEVIE.21.1-21.2; 21.14-21.17; 34.23- 34.28</p> <p>MAC.10.22-10.26; 39.1-39.2</p> <p>ERIKA. 10.8 - 10.16; 10.17 -10.18; 10.22 -26; 10.28 - 10.31; 11.1; 33.19 - 33.25; 42.10; 36.19- 36.20; 9.24 - 9.31; 10.2 -10.5; 10.25; 10.33; 11.11 - 11.23; 11.25 -11.28; 12.2 - 12.25; 35.17; 35.24 -35.26; 1.17 - 31.20; 31.28; 32.9 - 32.13; 41.18 - 41.33; 42.1 - 42.15</p> <p>PATRICK.9.1; 9.17-9.23; 31.1- 31.6; 53.20 - 53.29; 54.1 - 54.27; 55.4 - 55.5</p> <p>SHARON.48.17- 48.20; 57.9-57.23; 58.1-58.5; 60.13- 60.19-60.24; 61.2- 61.4</p> <p>KEVIN.12.3-12.9; 12.20-12.23; 27.1- 27.11</p>	<p>MATTHEW</p> <p>“Some physical, but not in the horrendous ways, but if a cake would fall – my grandmother was like my mother in spades. My mother was her eldest, and she got blamed for everything. You know, my grandmother did not like her... that she has never trusted women” “. She always gloried in being the intellectual equal of any man. The good side of that is that I have never been intimidated intellectually by a man” ZOEY</p> <p>“by the time it is in the Wall Street Journal in terms of finances it is old news ... and I show him on my iPhone I say, ‘what would you like to know? We can find out right now...He said, ‘well he have to cancel the Wall Street Journal.’ I said because it was 7 o’clock at night. I said, ‘I’ll call them now.’ We’ll call them in the morning I said, ‘no, I’m calling them now.’ Its his understanding about how the way works is correct for his times but its out of sync for this time... he’s like 9 to 5 Monday thru Friday kind of world and that’s how business is done and all sorts of stuff. That also kind of speaks to the letters; it used to be that if you got mail that it was something important. There was a reason for the correspondence.” “Well when we were growing up we did a lot of stuff together. We always did stuff together... Yeah, and although on Sundays my mom got the day off and my dad would take us out somewhere and we would do something together.” “Yeah, yeah, we spent time together and we had meals together... Because it was the 60s, 50s 60s” “That was a pretty good time. Umm... what I haven’t said and what therefore you don’t know is that when I was 14 I went away to school.” “So I was in fourth third or fourth grade so I was uhh... 8 or 9 years old it was 55 something like that. Yeah so that was part of it, the schools were not that good and then...” “It’s in the family yeah and umm... she would do things adjunctively with the business. For example, every year they would have a table-setting contest so they would like different organization, for charity, would set and they would do that in the stores. She did a lot of secretarial stuff; she could type a million words a minute and she ran the house like women did back in the late 50s and 60s. My father says my mother loved to have parties so they would have these parties, you know. Yeah, they were definitely 50s 60s kinds of parties and sometimes they would do themed parties.” JIM</p> <p>“Well, I don’t want to say anything about it. As far as my brother RBrother I don’t know. I was in, my father was in the jewelry business as was his father and his father put my father into the jewelry business when he got out of the war, World War II. He said I have a business for you to run even though he wanted to be an engineer “ “Well my grandfather had a jewelry store that originally evolved as was originally a pawn shop back so eventually it became a credited jewelry store and my grandfather bought the quote on quote Tiffany’s of Springfield, Hoffman Ring, because it was bankrupt and he said I have a store for you to run a business for you to run so my father being the creative type, he made a real go of it but it certainly wouldn’t have been his first choice of what to do but he did a great job” “so then I went into the business well I was, I graduated from college with a degree in experimental media, in film...</p>
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		<p>What do you do with that? How are you going to earn a living with that? So my parents of course are pushing that, oh yeah son's they're in the business. So there was this big push to push the kids into the business because that's what they did, okay?" "Whatever I don't know we had an interesting youth and it was a different era too." "My grandfather I think was rather conservative. But he was from, my father was from a different era and his dad was like completely different where they are putting palm 8 in their hair" "Oh worlds apart... I mean just huge. It is interesting to think about in those terms" "I think my grandfather and RBrother they probably talked conservative things together but my grandfather and I... I was apparently the apple of my grandfather's eye since I was the baby" BO</p> <p>"Yeah so my grandfather and my grandmother were very conservative. They were strongly Catholic they would go to mass all the five sisters together" "Right and my grandmother was into Spanish theaters. So they grew up in this, you would say, upper middle class family... were in the good families... they were sought after. My grandfather wanted all of them to become nuns you know that type." "Well going back to our norm, our culture how we were raised, there is all this politeness until she told me oh my god I was just not sensitive enough to know that and then she said 'well we need to talk about it again.' We always wait for the last minute instead of anticipating. Like me being the eldest sister I should have known that she was spending that much but she doesn't say anything until the last minute so there is again this whole diplomacy, which is really becoming a barrier" -STEVIE</p> <p>"Right, at dinner we are all suppose to be wearing our robes you know. So parents are always, you don't talk up or shout at them.. You didn't have to be a rich family to have that. Parents are always up there and you don't talk back to your elderly also your mom and dad." "Oh well they were faithful to one another. They stayed married. My mom and dad would have the fights. Even then my mom would be very naggy.... Oh I've seen him get very angry at times hit the wall I've seen him be patient but I have also known him to say 'I cannot live without your mom ... So she that why... he was a heavy smoker drinker get very load. My mom would feel small sometimes because being a socialite sometimes he would say the wrong thing on occasion." MAC</p> <p>"And my dad lived next door. And he was five years older than she was but they developed this romance when he was a senior in high school and she was you know younger. And they married when he was 21 and she was 16." "my dad was chauvinistic to a degree that he didn't think she needed to drive. If she needed anything, he would see that she got it. So when it was grocery shopping had to happen in the morning when he came home from work he would take her." "Yeah. And he actually worked two jobs. He would go from the Plain Dealer at night and would work at the machine shop for like four hours and then come home. So to send us to college. He was amazing. And he was willing to do that rather than have my mother work outside the home. So go figure. So I could never ask my parents for money to go buy clothes." "My dad didn't treat her as well as [Sister's Husband] treats me. "My mother's mother died</p>
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		<p>when she was 67. She dropped dead of a heart attack in a store downtown. But see the health care got so much better. My mother should not be living” “She didn’t drive. Now when ... when we were young my parents were involved in a serious car accident and the driver of the other car killed. And they were hit by a drunk driver. And so you can understand that my mother had a certain amount of fear of the responsibility of driving. And on top of that, my mother has always had a very .. a very low self esteem. She never thought she was worthy, that she was valuable. And she didn’t .. she went only through 10th grade of high school." "Yeah and as I told you before. Zero self esteem. I’m not smart enough to drive. I can’t do this. I don’t have good judgment. I go mom you do. You do.” “"And my mother always said I don’t know why your dad didn’t leave." m because we got married then in August and I have to say that um I wasn’t close to my mom after that. You know it was like I was now married and My Husband was my best friend and they didn’t really like him so they weren’t gonna like stop over for dinner or drop in. Nor did they invite us. But you know mom never got over it. She really never got over it" "And so when this conversation came up, I ended up crying to her. and I just I can’t believe that you still feel this way. I said he treats me better than dad treated you. 45 years later, same kind of story line being played out." ERIKA</p> <p>"she never drove. No, after my dad died in 91 she got her license. I think she drove one time to church. There are some people like that. She never felt comfortable driving she didn’t do it." “He was a quiet... he didn’t talk much umm... he always worked two jobs. He was smart with the money. I don’t think he made a lot of money but he invested and made some bad investments but he did well. All the kids got through college. He paid for I am sure a good portion for everybody. He paid for my schooling so he paid for everybody else’s. Just quiet, always working and growing up he worked midnight shift at the Plain Dealer so he during the day he would be sleeping” "Oh yeah when I was growing up we had a cottage near Chardon you know she would spend the whole summers out there with us. ... [Dad] would take us out there he would still work. He would just commute from there. He would sometimes stay over here on the week and stay out there on the weekends. when we were kids we didn’t have a car" "Well then Gbrother and Erika were old enough to drive at certain point back then but they weren’t always there. We had good times out there. My dad built this cottage when I was born late 50s so it was like a little summer community place to get away. Great fishing...Gbrother and Erika were lifeguards there, a lot of fishing, and there were all kinds of dancing at community hall. My dad was involved. It was a blast growing up there, resort type of thing. We had a great, growing up it was a blast. My parents were like partiers. They would have 30 people sleeping on the floor there on the weekends. They used to put me and pitch a tent and if there was any other company you know they would just put us a cross the street in a tent. All over the floor just flop all over. Yeah they had some wild parties back in the day." "We all do it. When you’re younger it’s easier to do but umm... we had a good upbringing. We had a blast parents were good parents." PATRICK</p>
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		<p>“It’s kind of hard cause we, when we were growing up was when a lot of, it was hard because we were broke a lot, I mean having a big family was just expensive.....so we struggled. So my parents didn’t get along a lot of the time, there was a lot of tension” “yeah, mom ran the house... Umm, oh God. Torturous. I mean torturous, they’ve been married for 61, 62 years. And for probably 50 years they fought heavily with each other. My mother can be very dramatic. She said she knew walking down the aisle that this is the wrong thing to do... She did. Well, she married him cause her first love went to the seminar” “She said, “I was just crushed.” She said, “I didn’t know what to do. My parents wanted me to marry this guy and so I just did and I knew.” She said, “I knew.” But whatever... She wanted to go to college but my grandmother wouldn’t send her to college. She didn’t think a woman should go to college” “It sure does. So they, I don’t know, they...for someone who had ten children, we kind of wondered. What? So when they’re done fighting, they make it (laughter) I don’t know how or when, she can’t tell me either so...but they’re just too strong type A, my mother more than my dad... she just, I mean, she was liberal way back when. She wanted her own car, she wanted to go to work, she didn’t want to stay with the kids” “She didn’t work, she worked with the youngest, when Jsister was young. And a little bit when Kevin was young... She worked at Jo Ann Fabrics. She was a clerk” “My dad never approved of her going to work.. He wanted her home making dinner. He’s very old school so” SHARON</p> <p>“Uh, you know, I don’t know if Sharon eluded to this, but my parents relationship has been difficult to say the least. Uh, it’s no secret. They survived each other for, I don’t know how long they’ve been married. 60 years? They were married in 54. Somehow they met and mysteriously had 10 kids. I have no idea how.... There’s no... I have never seen them really show any level of affection to each other outwardly, that I can remember” “it’s a miracle. And, you know, that’s why, if you imagine, 10 kids, having 10 kids over the course of 20 years. Each of our experiences are going to be different because the financial situation was different. There wasn’t a whole lot for any of us. But, the stresses on us individually were all really different” “They weren’t strong with each other. So... they were sort just surviving.. Yeah, for most of us it was just a matter of surviving. And, not seeing the parents, not seeing them either on the same page... getting mixed messages from them on a regular basis, you’re not really sure... it’s uh, you know, it’s not a strong level of stability... So, that’s how you can kind of see where relationships were all over the place depending on what was happening at that time between my parents and financially and with house, or, and then with each one of their own lives and the penalty of them just trying to figure it out...” KEVIN</p>
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Table 2. Interview Process Reflections

Themes	Identifier	Excerpts
<p>ERIKA: (good to talk about the problems of new caregivers getting info to cope with the process of caregiving; good to talk about the whole picture; able to evaluate caregiving role in a new way; nice to talk to someone out in the field - more people needed like this)</p> <p>PATRICK: (hoped he gave the right type of info - believed it was interesting to just talk; will look at resource book; RESEARCHER: (response to the conflict in Pbrother's story; it's like Mom is a prisoner in her mind and body, but also her environment; talks about caregiving as if it were a prison</p>	<p>ERIKA.73.22 - 73.33; 75.9; 75.14 - 75.15; 75.18 - 75.33</p> <p>PATRICK. 60.21 - 60.27; (15.1 - 15.28; 32.22 - 32.30; 42.1)</p> <p>KEVIN.50.1-50.3; 50.7-50.12</p> <p>SHARON.90.8-90.14-90.27</p>	<p>"Um, I guess it's kind of what I talked about most recently. And that is that I think people who find themselves in this situation with a parent, you know, don't know what help is available. And you know how to go about coping." "Well it's interesting that I haven't thought about the whole picture." "And I hadn't thought about that before. So this has made me kind of really evaluate my mother's situation and my role in it which I probably wouldn't otherwise thought of." "And I'm also. I mean very happy to talk with somebody like you who has interest in it because it definitely is a field that needs a lot more attention. .. One time we went to see Dr. Frankel and he introduced an .. an intern. A young girl. An Asian girl who was interested in geriatrics like psychiatry and I said to her, oh my gosh, I am so happy you're here...I said we need more people like you because you know there were only two doctors that my mother's internist recommended to me to help my mom." ERIKA</p> <p>"Hopefully I gave you some of the right type of information that you can use. It was interesting just to talk. I don't know I can't give you a specific answer there. Not really I'll look at the book and I'll let." PATRICK (RESEARCHER REFLECTIONS: "I FEEL SO MUCH CONFLICT, TENSION, UNSETTLED FEELINGS BY READING THIS TRANSCRIPT. I remember during the interview I had a general sense of discomfort being in this caregiving sibling's home. It was a modest, neatly organized house -from what I could tell from the living room. I felt safe, but it was empty - an empty feeling. Pbrother had dogs, which gave the house some life, but they also seemed suppressed - no personality. Bitterness, stress, strain. heaviness" "In Mom's condition, it is like she is a prisoner in her head, her body, and her environment - she gets aggravate because she can't go anywhere; she can't walk well." "Patrick talks about his sister's caregiving as if it were a prison sentence. He says, " Umm.. but like Erika did her time."</p> <p>"um, uh, no, I'm totally cool with it. If it helps, it helps. It's a unique experience having 9 brothers and sisters. Knowing that we all have different perspectives on our relationships with our, with my parents" "OH. It's different. You could write a book about all the different um things that we have experienced and our different view points. Um. You could write a play. Like 12 angry men or whatever. You could have 10 siblings and have them sitting around the table for the entire play and just reminisce and talk about things that we saw and our perspectives are all different and throwing them all together on the table would be really interesting." KEVIN</p> <p>"Oh, It just feels good to talk to somebody about it. Someone not in my family. ..And it's so ironic that your mom contacted me, because I have really just be pushing, the back of my mind creeping forward about going to find a support group. For someone else to talk to. Not my sisters and not my mom. Because I get their view all of the time. It's like in my head and I want someone else's view. SO, I think this was really perfect timing. It's good to talk to someone else." "Yeah. I was happy to do it. I thought it could help me and the fact that you have research is really a</p>

<p>sentence))</p> <p>KEVIN: (cool to help. Reflecting on different perspectives of siblings- could write a play about it)</p> <p>SHARON: (good to talk with someone outside the family; benefit of participating in the study was the info/research received; timing and readiness to open self up to new state of life for father and how to help in the situation)</p>		<p>driving force” “It’s just so much. I don’t even think I was ready to know more at that point. I couldn’t have done this last year, because it was just too fresh.” SHARON</p>
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